

Final Draft

**COMBATING ASTHMA IN THE
MID-ATLANTIC REGION:**

Conference Proceedings

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COMBATING ASTHMA IN THE MID-ATLANTIC REGION
Conference Proceedings

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Johns Hopkins University
School of Nursing
Baltimore, Maryland

Conference Hosted By:

Johns Hopkins University
School of Hygiene and Public Health
School of Nursing

Co-sponsored By:

U.S. Environmental Protection Agency
U.S. Department of Health and Human Services
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November 18, 1999

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EXECUTIVE SUMMARY

The U.S. Environmental Protection Agency, the U.S. Department of Health and Human Services, and the U.S. Public Health Service sponsored a two-day conference to examine the rise in asthma mortality and morbidity within the mid-Atlantic region (Region III) and to begin the development of a strategy to combat this increase. The Conference was held November 18-19, 1999 and was hosted by the School of Hygiene and Public Health and the School of Nursing at Johns Hopkins University in Baltimore, Maryland. The Conference sponsors invited recognized experts in the asthma field to attend both as panel members and as participants to target specific aspects of the asthma issue. One hundred and sixty-eight people attended the Conference, representing every state in Region III and a vast array of backgrounds and organizations, including: public health protection; clinical care; community-based organizations; health-insurance companies; Federal, state, and local governments; environmental protection; and academia.

The Conference had four main objectives:

1. To establish a network of public and private sector stakeholders who have an interest and a role in implementing the National Asthma Strategy
2. To provide an educational forum to exchange information about the public health, policy, and political issues pertaining to the asthma epidemic
3. To create a communications infrastructure among the asthma community
4. To serve as a catalyst for the development of new cooperative projects within the region

Conference participants were given many opportunities to network and to share ideas. The Conference was organized around formal panel discussions and a series of break-out sessions. Panel discussions focused on: public-health programs which address asthma; the disproportionate impact of asthma on poor and minority communities; and ways in which to influence change within managed health care. Break-out sessions explored the following asthma-related issues: setting the research agenda for action; evaluating the information infrastructure; monitoring air quality; education and outreach; health-care interventions; and environmental interventions. Participants were encouraged to develop lists of priorities and recommendations that could be used to provide a foundation for a regional strategy to address asthma. Participants were also encouraged to identify barriers which they have encountered in their attempts to combat the

disease.

A number of key themes emerged from the Conference. Participants recognized that the incidence of asthma morbidity and mortality is increasing. In fact, the number of people affected by asthma has doubled over the last 15 years. Much of the increase has been among young children. This phenomenon is occurring at the same time that significant improvements are being made in the types of medication and other tools available to fight the disease. In addition, members of poor and minority populations seem to be disproportionately impacted.

Several reasons for the increase in asthma incidence were discussed. Among them was the fact that most people are spending more and more of their time indoors. Participants noted the growing importance of addressing environmental triggers, such as dust mites, as part of a comprehensive asthma management plan for patients. The group recognized that addressing only one pollutant, such as environmental tobacco smoke, would not solve the asthma problem. Instead, solutions must be multi-faceted and address all dimensions of a person's life: home, school, workplace, etc.

The need for effective asthma education was another major theme which emerged from the Conference. This issue was mentioned in almost every break-out session and panel discussion. The need for education is at all levels, ranging from the patient to their families to their schools and their primary-care physicians. The group discussed the value of written materials versus interactive training, as well as the barriers that they perceive limit their ability to educate people about asthma management.

The need for appropriate measures of success was also identified. Participants grappled with how to evaluate the effectiveness of various interventions in terms of quantifiable data. Measures such as asthma-related hospital admissions and emergency room visits were easy to track but do not necessarily tell a complete story. School absenteeism and work days missed, including those missed by parents caring for asthmatic children, were identified as well. However, the group also wrestled with more subtle indicators, such as quality of life, the ratio between the use of rescue medications versus prevention medications, and the ability of patients to manage their asthma. The importance of these measures was realized by everyone and felt to be key in shaping a strategy to attack asthma, both on an individual and a regional level.

Several issues were also discussed that were specific to the efforts of Region III. The group felt

that stakeholder involvement was essential to the successful development of a regional strategy to attack asthma. The Conference sponsors characterized the meeting as the beginning, rather than the end, of this process and expressed a desire for continued stakeholder input. Region III is home to a high concentration of not only urban areas, but also academic institutions. The asthma issue is a hot topic in the region; many activities are currently underway to address it. The opportunity to share the results of these activities and to learn from one another was considered to be a catalyst for coordinating and enhancing the effectiveness of future stakeholder efforts to combat asthma.

Participants in each of the break-out sessions were asked to generate a list of priorities, recommendations, and barriers to success based on their involvement with the asthma issue. The details of these break-out sessions are provided in the body of this document. The majority of the priorities and recommendations identified fell into five areas: Communication; Education; Health Care; Environmental Intervention; and Data Collection. The need for better research is implicit within each of these five areas. However, to fully understand the context of the recommendations and priorities, it is necessary to first understand the barriers which are presented below.

BARRIERS

A broad range of barriers were identified by the group; some were specific to an individual's particular situation, others were more broadly applicable. Several barriers were discussed again and again both within the break-out sessions and within the panel discussions and were related to health-care providers, patients and their families, and managed-care organizations.

Health-Care Providers

The group felt that better education of health-care providers was essential. Primary-care providers are not: accurately diagnosing asthma; asking the right questions of their asthma patients; following established asthma guidelines; spending enough time with their patients to adequately assess them; and prescribing proper asthma medications and management tools such as peak-flow meters. The group expressed a great deal of frustration, particularly around the propensity of physicians to misdiagnose asthma as bronchitis and to treat it with antibiotics. In some cases, Conference participants had their own efforts to manage a child's asthma undermined by an emergency room physician who told the parents that the child had bronchitis, not asthma.

Patients and Their Families

A patient's inability to manage his or her asthma was also a frustration shared by the group. Patients are prescribed medications that they never obtain. They do not follow their asthma management plans. They rush to the emergency room rather than beginning treatments at home. Oftentimes, they do not feel that they are capable of managing their illness, so they relinquish their control to emergency room physicians who may or may not recognize their symptoms as asthma. One attendee at the Conference talked about a "poverty of mind." Not only are many asthma patients and their families materially poor, but they also suffer from a "poverty of mind." They believe that they are poor and that they have no choices. This attitude can affect their confidence in their ability to manage their child's asthma. Until people learn to trust themselves and their abilities, it will be very difficult to effectively manage asthma within these types of populations.

The group also discussed a number of institutional barriers that affect the ability of patients to self-manage their asthma. First among these was the limitations on children carrying inhalers at school. The group felt that children were afraid to bring their inhalers to school for fear of being expelled or suspended. Another barrier identified was the difficulty in obtaining information from schools on asthmatic patients due to confidentiality considerations. Without a sense of absenteeism and other factors, such as the frequency of use of rescue medications at school, it is difficult to evaluate the effectiveness of intervention measures on a patient's management of the disease. Finally, the group expressed concern about the lack of school nurses and the fact that most teachers and administrative staff do not understand the symptoms of asthma and are not trained in asthma management. Participants felt that children spend a large portion of their day at school and that schools have a responsibility to their asthmatic students to have someone on campus at all times who can provide assistance to an asthmatic in trouble. In addition, such a resource can provide students support and training if necessary.

Managed-Care Organizations

Managed-care organizations were also seen as a barrier to the effective management of asthma. The group identified several areas of concern. The first had to do with coverage of asthma medications and equipment. Participants spoke about the difficulty in getting managed-care organizations to routinely cover peak-flow meters or a second inhaler for use at school. There was also a discussion about non-formulary medications and the natural tendency for patients to use only those that are on the formulary, rather than those that are not covered by their insurance.

company. Unfortunately, some of the more effective asthma medications may not be on a particular insurance company's formulary list.

A second concern related to the difficulty in getting managed-care organizations to respond to patients. It can take months to get approval for a peak-flow meter or a non-formulary medication. Patients give up before their issues get resolved. They also frequently do not understand their benefits and have difficulty obtaining information from their insurance companies.

The group also felt that managed-care organizations prevented primary-care physicians from taking the necessary time to fully educate their patients about all aspects of the disease. In an effort to move patients through the system, physicians are discouraged from taking too much time with any one patient. In addition, physicians are not compensated for the time they take educating patients.

A final barrier concerned employee coverage. Managed-care organizations provide employers with a number of health-plan options when they are selecting their benefits packages. A managed-care organization may have aggressive disease-management programs in place which would address many of the above barriers, but the health-plan option selected by the employer does not allow his or her employees access to these types of programs.

PRIORITIES AND RECOMMENDATIONS

The following discussion highlights key priorities and recommendations identified by the group. As mentioned before, these fall into the following five areas: communication, education, health care, environmental intervention, and data collection.

Communication

A number of issues related to communication were discussed during the course of the Conference. The group felt that there was a strong need to improve communications among the various parties associated with managing a patient's asthma, including primary-care providers, specialists, hospitals and emergency room staff, school nurses and teachers, and health-insurance companies. Participants recommended that physicians take more time with their patients to teach them to manage their asthma and to verify that they are using their medications and other asthma

management tools (such as spacers and peak-flow meters) properly; insurance companies must allow physicians more time to do this. The group also recommended that a mechanism be established to allow information about hospital admissions and emergency room visits to be automatically transmitted to patients' primary-care physicians, any specialists that they may be seeing, and to their school nurses. In this way, all those involved in a patient's care can be informed of any change in his or her health status. Participants also strongly recommended that health-management organizations provide dedicated staff to troubleshoot situations and to provide prompt resolution to benefits problems concerning asthma patients. For example, patients often experience difficulty obtaining spacers and inhalers for both school and home. And yet, many times, insurance companies will allow this duplication in medications, but only after a pharmacy or health-care provider obtains special permission. This can be a long, cumbersome process.

The group also discussed issues surrounding cultural differences in approaching asthma and allergies and observed that some parents may not understand the long-term management aspects of the disease. They may be concerned about the use of daily medications and may feel that it is unnecessary to take a child to the doctor if he or she well. Similarly, health-care providers need to understand their patients' circumstances; it may not be easy for a parent to obtain the necessary medications for their child due to a lack of money or transportation. At the same time, health-care providers need to understand the environment in which their patients live. Something at home may be exacerbating an asthma problem. All of this information can best be obtained by communicating with the patient and his or her family during an office visit or through home visits.

Education

Linked closely with improving communications is the need for improved asthma education. The group felt that many different types of people needed additional education. There was a great deal of discussion about better educating primary health-care providers and their office staffs. Medical schools and nursing schools do not provide adequate information about diagnosing and managing asthma to their students. This results in frequent misdiagnosis of asthma, particularly among young children. Similarly, the National Asthma Education and Prevention Program (NAEPP) has developed guidelines for the management of asthma. However, despite their efforts, the NAEPP has found that these guidelines are not being widely implemented by health-care providers around the country. Based on these experiences and others like them, the group recommended efforts be made to better educate health-care providers.

The group also discussed the need to provide asthma education in schools. Several participants discussed the success they had had in offering the American Lung Association's (ALA) "Open Airways" program to schools in their area. This program was recognized as an invaluable resource to educate children between eight and 11 on how to manage their asthma. A similar program "A is for Asthma" is available for preschoolers. In addition to these resources, the group recommended that both teachers and school nurses have a better understanding of asthma and how to manage it given that they play such an important role in the lives of asthmatic children. They should be trained to look for clues that a child's asthma is out of control, such as an unwillingness to participate in gym classes. School nurses should be equipped to provide nebulizer treatments at school and to help children use their inhalers properly.

Educating patients about their disease and how to manage it is also essential. The group recognized the need to empower patients and their families through education. Children need to know how to use their inhalers properly and to recognize what their bodies are telling them. Parents need to know how to manage an asthma crisis and to have confidence that they can do it. Families need to be connected to primary-care providers who can assist in this process. By empowering the patients, the group believed that costs associated with emergency room visits and hospital admissions can be driven down.

The group also recognized the value of communities in the war against asthma. Churches and other community-based organizations can provide opportunities for asthma training and can work with families to better understand how to manage the disease. These types of organizations can also be used to conduct or support environmental interventions in the home. Many of these groups recognize the significance of asthma, particularly in terms of poor and minority populations, and are willing to help in outreach efforts.

Health Care

Issues related to health care were touched upon in several contexts. Key to the successful management of asthma is the successful administration and use of asthma medications. The group talked about the frustration of prescribing medications, only to find that the prescriptions were never filled. This can result from a lack of understanding about the importance of the medications and what they do or from logistical issues such as being unable to get to the pharmacy to have the prescription filled. Resolving this problem may require that health-care providers take more time to explain things during an office visit, as well as follow up with their patients after they have been seen.

The group discussed the need to equip school nurses to take an active part in a patient's asthma management plan. This includes providing them with nebulizers, inhalers, spacers, and other asthma management tools. The group suggested that school nurses monitor a child's asthma action plan, at least while he or she is at school, and provide additional training and support to the child. If a school does not have a nurse, then a teacher or administrator should be trained to administer asthma medications and evaluate a child's health status in an emergency.

Environmental Intervention

The relationship between environmental triggers and asthma is now better understood. In addition to medications, the group discussed the importance of ridding the environment in which an asthmatic lives of triggers, particularly in the bedroom. These triggers can include environmental tobacco smoke, cockroaches, dust mites, mold, and ambient pollution. Information about several programs that conduct home-intervention studies was presented. The group also recognized the importance of the school environment and recommended that schools follow EPA's *IAQ Tools for Schools* as a means of improving the indoor air quality of their buildings. In addition, participants recommended enforcement of smoking bans on campus and ventilation standards. This latter recommendation is also applicable to public buildings, especially multi-family housing. The group touched on the need for environmental approaches to be holistic; in other words, intervention strategies must address multiple triggers. Finally, the group recommended that managed-care organizations support and cover costs associated with the environmental management of asthma, such as pillow and mattress covers.

Data Collection

Data collection was also a key concern for the group. A number of key data needs were identified, including medical coverage and insurance use, hospital-use rate, asthma drug use within different socioeconomic brackets, and school/work absenteeism. The group also highlighted the need for local data. The group discussed the status of existing data and noted that many of the databases that exist cannot be linked, thereby limiting their utility. Similarly, concern was expressed that the data that do exist was of questionable quality in some cases. The group strongly voiced the need for high quality data that can be compared among multiple sources and identified the following three priorities: (1) the need for and collection of new data, (2) the need to better utilize existing data, and (3) the need to make all data more user friendly.

CONCLUSION

Conference attendees represented a broad range of backgrounds and disciplines. During the two days that they were together, participants had the chance to work with people that they do not normally encounter. The Conference provided a neutral forum in which individuals from different organizations could come together and work toward a common goal. The group felt that this was an invaluable function of the Conference. By setting aside personal agendas based on who they represented, participants were able to exchange ideas and establish relationships. The Conference generated innumerable partnering opportunities, particularly in terms of sharing information among health-care providers; sharing research results among researchers, the public, and Federal agencies; developing outreach materials; and acquiring and/or financing the technologies necessary to collect data and use it effectively. Each person was asked to think about what he or she could do to combat asthma. People were then asked to commit to tackling some aspect of the issue. These aspects were organized into five areas: (1) data and monitoring, (2) education and communications, (3) health care, (4) environment, and (5) research. The Conference organizers explained that a smaller group would be reconvened at the end of January to check on the progress made to implement the recommendations and priorities identified. In the meantime, those that attended the Conference and those that were invited but could not attend were encouraged to review and make comments on these proceedings. A copy of this report is available on EPA's Region III website at www.epa.gov/Reg3artd/.

The text of the proceedings is organized into two days. The first day includes a summary of the panel discussions and the break-out sessions. The second day includes a summary of the panel

discussions, as well as the wrap up session for the Conference. The report also includes two appendices. Appendix A is a list of Conference attendees. Appendix B provides a list of participant commitments. EPA, HHS, and PHS are still seeking stakeholders to volunteer to become part of the groups listed in Appendix B.

DAY ONE
November 18, 1999

1. OPENING REMARKS

1.1 *John Groopman, Ph.D., Department of Environmental Health Services, School of Hygiene and Public Health, Johns Hopkins University*

Dr. Groopman opened the Conference by sharing his boyhood memories of driving through Baltimore when the sky was yellow. Pollution was visually evident in those days. Today we recognize that pollution is evident at a much more insidious level. Dr. Groopman then observed that 80 percent of the U.S. population live in an urban setting. The average American only spends about 30 minutes per day outdoors. These statistics suggest a significant change over the last 20, 30, and 40 years in the pattern of people's exposure to pollution. Similarly, the increase in the incidence of asthma reflects a change in the pattern of the disease—asthma in children has doubled in the last 20 years. Dr. Groopman concluded his remarks by playing a game with the audience which demonstrated that scientists looking at the same data can come up with disparate answers and interpretations. Relating the results of this game to the asthma issue, Dr. Groopman noted that it is often difficult to gain agreement among scientists about what the data related to asthma incidence really mean.

1.2 *W. Michael McCabe, Acting Deputy Administrator, U.S. Environmental Protection Agency (formerly Administrator, EPA Region III)*

Mr. McCabe discussed the importance of the Conference and expressed his appreciation for the collaboration among the U.S. Environmental Protection Agency (EPA), the U.S. Department of Health and Human Services (HHS), and the U.S. Public Health Service in making the Conference a success. The Conference organizers sought to bring the best minds together to lay the ground work for action on what has become a health crisis. He felt this effort is a good example of how these departments can work together to bring resources to an issue such as asthma. Mr. McCabe then went on to explain that EPA is in the business of protecting public health from pollution – air should not hurt you. He further explained that this administration has set some of the toughest air quality standards in a generation. Unfortunately, the courts have not always agreed, and in some cases, such as particulate matter, they have prevented the Agency from implementing them. However, EPA remains committed to protecting public health through a variety of tough standards. For example, the Agency is taking action to reduce the amount of sulfur in gasoline. It

is also exploring tightening up tailpipe standards for larger vehicles, such as sport utility vehicles (SUVs). It is Mr. McCabe's hope that these types of standards will help people who are suffering from asthma.

Asthma is at epidemic proportions. Approximately 5.5 million children are affected, resulting in approximately 150,000 hospitalizations each year. There has been a three-fold increase in the number of deaths in the last ten to twenty years – 280 people died from asthma in 1995. Over ten million school days have been missed by children with asthma. Medical costs rose from \$6.2 billion in 1990 to \$14 billion in 1996. In addition to children, asthma affects thousands of adults.

Mr. McCabe observed that we are all aware of asthma as a public health issue. By pooling the expertise of the various stakeholders, the Region can develop an effective strategy to deal with the growing asthma epidemic. Mr. McCabe noted that Region III was the first Region to take steps to implement President's Clinton's National Asthma Strategy. He also noted that the challenges are difficult, but expressed his confidence that the Region will make great strides in combating asthma, based on the experience, in-depth knowledge, and active participation of the Conference's attendees. He concluded by stating that these components for progress are vital to the success of the Conference and to the strategy the Region develops.

1.3 *Lynn Yeakel, Regional Director, Department of Health and Human Services*

Ms. Yeakel shared with the audience her own childhood asthma experiences – trips to the emergency room, hospitalizations, sleeping sitting up in order to breathe, and not being able to participate in sports. Consequently, she is proud of the role that HHS is playing with EPA in tackling the asthma issue in such a serious manner. Ms. Yeakel explained that the challenge of the Conference is to develop a Regional strategic plan to combat asthma throughout the mid-Atlantic states. Participants are all stakeholders in this process and were invited to the Conference to assist in getting the process off the ground.

Ms. Yeakel echoed Mr. McCabe in observing that Region III is the first to develop a Regional plan and suggested that this is a good opportunity to provide leadership. She went on to explain that in 1997, President Clinton created the Task Force on Children's Environmental Health, co-chaired by Donna Shalala and Carol Browner. This task force, which is comprised of nine Federal departments and six White House offices, chose asthma as one of its four priority areas. Ms. Yeakel believes that this ongoing leadership and collaboration is a good thing.

Ms. Yeakel reviewed the President's FY 2000 budget request of \$68 million in new funding, in addition to the \$120 million in the existing HHS budget for ongoing asthma-related activities and research. These activities involve a variety of players within HHS, the foremost of which include the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). Ms. Yeakel went on to discuss an evaluation project, managed by the HHS Office of Disease Prevention and Health Promotion, which is designed to assess health care for asthma in poor and minority communities. These communities are disproportionately burdened with asthma. This project is being conducted by the Association of Clinicians for the Underserved and the Clinical Region Action Network to understand the barriers to reaching out to these populations that are most affected.

In addition to its participation on the President's Task Force, HHS has launched an intra-department strategy called "Action Against Asthma." This program covers all asthma patients and all aspects of asthma. Ms. Yeakel also discussed Congress' interest in asthma this year and noted that several initiatives and bills were introduced, although none have been enacted. She noted several recent attempts within the Region to coordinate asthma activities: (1) the Philadelphia asthma task force, (2) the Virginia summit to develop a statewide action plan, and (3) the asthma coalition in southeastern Pennsylvania, which is being led by the American Lung Association (ALA). Ms. Yeakel encouraged participants to exchange information on these and other efforts throughout the Region to identify what has worked and what has not worked. This information will be important to the development of a Regional strategy.

Finally, Ms. Yeakel concluded by observing that the Region has many wonderful resources and that it is incumbent upon stakeholders in this process to make use of all of these resources in determining how to solve the asthma problem. She also encouraged participants to take the opportunity to form partnerships and collaborations that will continue after the Conference has ended.

2. FIRST THINGS FIRST: INFORMATION FOR ACTION

2.1 *Dalton Paxman, Ph.D., Senior Environmental Health Advisor, Office of Disease Prevention and Health Promotion, Department of Health and Human Services*

Dr. Paxman opened this session by describing the way in which conference participants were selected. Each agency was contacted personally and asked to identify the leaders in the asthma field. These individuals were invited to the Conference. Dr. Paxman then charged conference participants to begin implementing what has happened at the national level. Dr. Paxman stated that the morning session was devoted to developing the information necessary for decision making. The morning panel was to provide the background, the context, and the framework for identifying the nature and type of information needed to develop a Regional strategy. In addition to the panel discussion, the agenda included a number of break-out sessions later in the day, which were designed to gather stakeholder input on the priorities and recommendations regarding information needs for the Region.

2.2 *Judith M. Katz, Director, Air Protection Division, U.S. Environmental Protection Agency, Region III*

Ms. Katz discussed the importance of the Conference and the reasons for bringing the group together. She expressed her enthusiasm for working with stakeholders to develop and implement a strategic plan to combat asthma. Ms. Katz acknowledged that EPA cannot accomplish this alone and is focusing on ways to work cooperatively with all the stakeholders to lessen the impact of asthma in the Region. Asthma is a difficult health issue – asthma mortality and morbidity is increasing rapidly, especially among children. Region III has chosen to aggressively tackle the asthma issue because the Region is home to a high concentration of urban areas, as well as a high concentration of academic institutions and people who are knowledgeable about the issue. These two factors offer a unique opportunity to combine efforts to address the asthma problem.

Ms. Katz went on to describe the Conference's four objectives: (1) to establish a network of public and private sector stakeholders who have an interest and a role in implementing the National Asthma Strategy, (2) to provide an educational forum to exchange information about the public health, policy, and political issues pertaining to the asthma epidemic, (3) to create a communications infrastructure among the asthma community, and (4) to serve as a catalyst for the development of new cooperative projects within the Region. Ms. Katz recognized that the Conference would not be able to address every issue regarding asthma in the Region and encouraged participants to keep in mind that the Conference is just the first step in the process of

developing a Regional plan. Ms. Katz explained that the Conference would offer many opportunities for participants to highlight current activities and to propose new initiatives.

Ms. Katz concluded by informing the group that a report will be generated at the end of the Conference. This report will be the genesis of a strategic plan, and will be sent to all Conference participants. Participants will be able to comment on the report, and those who were unable to attend will be able to review the report at EPA Region III's website (www.epa.gov/Reg3artd/).

2.3 *Stephen Redd, M.D., Director, Air Pollution and Respiratory Health Branch, National Center for Environmental Health, Centers for Disease Control and Prevention*

Dr. Redd spoke on two main topics: (1) the status of asthma in the United States and (2) initiatives taken at the Federal level to combat the asthma problem. He provided the following data on the impact of asthma to the nation:

- The number of people affected by asthma has doubled over the last 15 years. The most rapid increase in the number affected has been among the youngest children.
- The number of deaths from asthma has increased rapidly over the last 20 years from a low in 1977. Older people are more likely to die from asthma than are young children.
- \$1.6 billion was spent on asthma care in 1994, including \$235 million on medicines and \$182 million on emergency department services. These latter expenses could largely have been averted through better management of the disease.

Asthma affects every population group within the United States, regardless of age or race. However, the measures of severity of the problem are not spread equally through society. The hospitalization rate is much higher among African Americans than among whites. So, while it is fair to say that the problem affects everyone, some groups are more affected than others.

Dr. Redd explained that recently there have been several important changes in the recommendations for asthma management. The medical community now encourages more extensive use of objective measures of lung function. There is an increasing reliance on the use of preventative drug therapy and an increasing recognition of the importance of environmental exposures in exacerbating asthma.

The CDC is currently researching asthma interventions in an attempt to identify effective strategies that can be utilized from a public health perspective. The Agency is looking at developing a case study model that can be shared with others. Dr. Redd observed that lots of groups are trying many different things and, to some extent, recreating the wheel. The CDC would like to help groups learn from others' experiences.

Dr. Redd described several Federal initiatives:

- **Healthy People 2010:** This is a document and a process to identify health objectives for the nation. This effort takes place every 10 years. In the 2000 report, three objectives for asthma were identified: (1) reduce the mortality rate, (2) reduce the hospitalization rate, and (3) reduce the emergency room use rate. The 2010 report includes an entire chapter on respiratory diseases, with two-thirds of the objectives listed related to asthma. In addition, process markers have been identified to measure the quality of care delivered. These markers include primary health-care provider counseling on using inhalers and spacers correctly, as well as making environmental modifications to alleviate disease symptoms. The report also includes a goal to implement state survey systems for asthma. The complete set of objectives (maybe five to six hundred) will be released at a meeting scheduled for late January.
- **Action Against Asthma:** This document was released in March 1999. It is the product of work throughout the Department of Health and Human Services and includes four components designed to: (1) determine the causes of the asthma epidemic, which are necessary to develop interventions to prevent the disease from occurring, (2) reduce the burden on people who have asthma through improved treatment and new research, (3) eliminate the disproportionate impact of asthma among minority populations and those living in poverty, and (4) develop systems to better track the disease and assess the effectiveness of asthma intervention programs. This document can be found at www.aspe.hhs.gov/sphome.htm.
- **Asthma and the Environment: Strategy for Children:** This document is very similar to the Action Against Asthma document described above. In particular, it focuses on children and highlights the environmental components of asthma. This report can be found at www.health.gov/environment/fin.pdf.

Dr. Redd also provided the group with a legislative update. He related that the proposed \$50 million disease management program is not likely to be authorized this year. However, the FY 2000 budget will probably contain money for EPA to: (1) invest in school programs to decrease children's exposure to allergens and to train school personnel to help people manage their asthma better from a school setting, (2) provide information to help avoid allergens and triggers for

asthma through a widespread media campaign, and (3) conduct research on the environmental causes of asthma. An excellent website for obtaining legislative updates is www.thomas.loc.gov.

Dr. Redd ended his talk by stressing the importance of asthma as a public health problem. He noted that action is underway, but that more is needed. He hoped that action taken at the Regional level as a result of this Conference would be a first step in the process of converting some of the strategies talked about at the national level to local programs that would positively affect the lives of people with asthma.

2.4 *Peyton Eggleston, M.D., Professor of Pediatrics, School of Medicine, Johns Hopkins University*

Dr. Eggleston opened his remarks by noting that asthma continues to be an increasing problem. The Northeast Region (which he felt was more representative of Baltimore) leads the country in the number of asthma-related hospitalizations. He spoke extensively about the activities of the Center for the Asthmatic Child in the Urban Environment, which is supported by the EPA, NIEHS, and CDC, and operates under the auspices of the Johns Hopkins University. Dr. Eggleston explained that there are eight centers for children's health scattered throughout the country. Five of the eight address the asthma problem. The overall goal of these Centers, which were initiated last summer and fall, is to develop data about the impact of the environment on children's health.

Dr. Eggleston explained that the Center at Johns Hopkins is a joint effort between the School of Medicine and the School of Hygiene and Public Health. Its goals are to: (1) examine environmental causes or relationships with asthma morbidity with the idea that environmental relationships are important and (2) develop an intervention strategy which can be tested and promulgated if successful. Dr. Eggleston then described a number of projects that the Center is conducting to meet these goals:

- One study is looking at genetic markers in terms of their responsiveness to ozone. Eventually this study will be expanded to look at other pollutants.
- Another study is being conducted to establish a clear mechanism to better understand the interaction between particular pollutants and allergens in a child's environment. This study is based on the premise that inorganic particulates may enhance allergen-induced inflammation of the airways.

- A third study is being conducted to identify the role of pollutants and allergens in asthma morbidity. This study has been designed as a case control study.
- A final study is being conducted to develop a global treatment program to reduce pollutant and allergen exposure. This study has been designed as a community intervention trial.

These latter two studies are both focused on indoor exposures, such as those occurring in the home environment.

Dr. Eggleston spoke of the partnership being formed between the Center and the East Baltimore community. Investigators are working to provide community input into the treatment program and to form channels for bringing information back to the community. The Center is also serving in an advocacy role for improved housing in the community. Members of the community are very excited about this aspect of the Center's involvement, but Dr. Eggleston stressed that the primary goal of the Center is to develop new research information to better understand the role of the environment in urban asthma.

To this end, the Center has been located in one of the poorest urban areas in Baltimore. Investigators are addressing three aspects of the urban environment: bioaerosols, air pollutants, and the social environment. This latter aspect is important to controlling exposure and the management of the disease. The Center is working with five elementary schools as a means of addressing the community that surrounds them, sharing their findings, and examining the environment within the community. Although they consider that a great deal of exposure occurs in the home, Center investigators are also monitoring ambient pollutant levels. They are conducting intervention studies in which they are going into people's homes, examining the housing stock, and evaluating the exposures to allergens and pollutants within these homes. They are relating indoor exposures to ambient pollutant levels, as well as to asthma morbidity. Treatment is based in the home, not only for obvious problems such as infestations or molds, but also for things like NO₂, which can result from cooking with gas in a poorly ventilated area, ambient pollutant levels, and cigarette smoking. The Center has gone so far as to sponsor smoking cessation programs within the community. The community has been very supportive of the Center's activities and feels as though there is finally someone who will help them deal with housing-related health issues.

2.5 *Captain Anita W. Batman, M.D., DABFP, Regional Health Administrator, Public Health Service, Region III*

Dr. Batman spoke about the importance of stakeholder involvement in the development of a Regional strategy to combat asthma. She observed that Region III is developing a plan with a slightly different approach. Dr. Batman noted that the Region has presented the following goals to the audience: (1) determining the causes of asthma, (2) reducing the burden to asthmatics, (3) eliminating the disparity among population groups, and (4) creating systems for tracking and assessments. The Region has also made a strategic decision to let the people doing the work make the plan. Consequently, Dr. Batman advised the group that this was their plan – it will be whatever the stakeholders make it.

To improve the chances for success, Dr. Batman echoed Dr. Paxman's remarks in explaining that the Region had invited everyone they could find from the fields of health care, medical primary care, public health, environmental protection, research, epidemiology, advocacy, and public education. She reminded the group that no one discipline can accomplish the above goals alone – all of these fields are interconnected. In planning the Conference, the organizers listened to what the stakeholders said and designed the agenda to ensure that key issues were discussed. Dr. Batman expressed that once the Conference is over, the input and the recommendations provided will be invaluable. She explained that at the very least, participants will have had the opportunity to get to know one another. At the very best, they will have created a framework by which the Region can begin to implement a plan. Dr. Batman concluded by expressing her belief that the Region should be able to provide the resources necessary to create a framework to support what the stakeholders are doing so that they can remain connected with each other.

2.6 *Elaine Wright, Deputy Director, Air Protection Division, U.S. Environmental Protection Agency, Region III*

Ms. Wright stressed the theme of “building” in her remarks – building partnerships and networks among the 130 people attending the Conference. She noted that everyone in the audience had demonstrated their interest and their commitment to combating asthma by their participation in the Conference. Ms. Wright spoke about her vision of what would constitute a successful Conference – information sharing. People sharing their ideas and their suggestions; doctors talking to researchers. She expressed her thought that since people generally tend to talk to people like themselves, new ideas are sometimes difficult to generate. However, she explained that the break-out sessions were designed to provide an opportunity for people to “mix it up.” She told the group to listen to what other groups are doing that works. In conclusion, Ms. Wright stressed to the group the importance of walking away with a set of ideas that can be used to develop a Regional strategy.

3. MORNING BREAK-OUT SESSIONS

3.1 Break-out Session #1: Science: Setting the Research Agenda for Action

Discussion Leaders: *Reynold A. Panettieri, Jr., M.D.*, Director, Asthma Program, University of Pennsylvania Medical Center
David M. Lang, M.D., Thomas Jefferson University, Jefferson Medical College

Dr. Lang opened this session with a description of two projects with which he has been involved. The first project tracked the rates of death in Philadelphia due to asthma from the mid-1970's to 1997. These data clearly show an overall trend towards increasing deaths from asthma each year. These data also indicate that the factors driving asthma-related mortality are continuing to operate. Dr. Lang suggested that an attempt should be made to identify the factors that are driving these trends.

Dr. Lang also described a study of local high-school athletes. These athletes participated in a free running exercise in which they were asked to run one mile around a football field. After they finished running, their peak-flow rates were measured. Nine percent of the athletes participating exhibited symptoms of exercise-induced bronchospasm. Thirteen percent of the African-American athletes participating in the study exhibited these symptoms. In addition, a linear correlation was found between the athletes affected, who had a previous history of wheezing, and the rate of poverty in the zip code in which they lived. Most significant, however, was the fact that bronchospasms only existed in those athletes with no history of wheezing if they resided in an area with a high poverty rate. These data are consistent with studies performed in other areas of the world and demonstrate the importance of environmental determinants in the incidence of asthma. In fact, as Dr. Lang stated, the best markers for environmental determinants are urban, poverty areas.

Dr. Lang cited studies that indicate that Americans spend as much as 22 hours per day indoors. He noted that house dust, dust mites, and cockroach infestations, all common indoor pollutants or allergens, have a significant impact on asthma incidence. He also observed that these factors are very difficult to control and require effective intervention strategies.

Dr. Lang concluded his overview with a series of slides that demonstrated a seasonal pattern to the rate of hospital admissions for asthma. The rate is relatively low in the summer and then

increases significantly in the fall. On the other hand, mortality data does not appear to have a seasonal pattern. This suggests that the risk factors are different for asthma mortality versus asthma morbidity. He also presented a series of slides which showed pollen rates, ragweed, and mold spore count, noting that mold spores are the least understood allergen.

Dr. Panettieri followed Dr. Lang and reviewed the data on the direct costs of asthma. These direct costs include medicines, hospitalization, emergency room visits, and ambulatory visits. The driving costs are those associated with hospitalizations and emergency room visits. For children less than 17 years of age, \$0.84 billion is spent annually; \$3.51 billion is spent annually by adults over the age of 17. Dr. Panettieri also noted that the morbidity and mortality rates for asthma are disproportionately higher for inner-city, low-income asthmatics. These rates are higher for children, African Americans, and Hispanics. He observed that we typically think this imbalance results from inadequate access to medical care, but we must realize that cultural differences in how allergies are managed may also contribute. Dr. Panettieri also wondered how patient adherence to asthma management plans can be improved. He noted that although we have the best therapies available to us, asthma morbidity continues to increase.

Dr. Panettieri went on to point out that evidence-based asthma guidelines do exist and yet we still struggle with why they are ineffective. These guidelines are one of two thousand that are sent to primary-care physicians each year, and it would be impossible for every physician to incorporate the multitude of guidelines they receive into their day-to-day practices. Consequently, Dr. Panettieri believes that the guidelines, which call for the use of corticosteroids, emergency plans, and spirometry, are underutilized. Dr. Panettieri explained that the effective use of spirometry is essential in making a correct diagnosis of asthma and expressed concern that primary-care physicians were not more aggressive in its use.

Dr. Panettieri described what he believe to be the key components of delivering good asthma care:

- Improved access
- Improved adherence to therapy through patient education
- Establishing a correct diagnosis (25% of patients have been incorrectly diagnosed with asthma)

- Aggressive medical therapy

He related to the group his approach to disease-based management, which includes sending a nurse to the primary-care physician's office rather than to the patient's home. In this way, the nurse can educate not only the patient, but also the office staff and the physician. This approach has proven very successful and has resulted in a reduction in asthma hospitalizations.

Dr. Panettieri concluded his talk with a series of questions:

- What is the prevalence of misdiagnosis of asthma in the primary-care setting?
- Can predictive models be developed to identify patients who are not correctly diagnosed?
- Does misdiagnosis of asthma have informed consequences?
- Do primary-care physicians use or want to use objective measures, such as spirometry, to diagnose asthma?

Dr. Panettieri noted that these questions do not incorporate the concept of triggers.

3.1.1 Hot Issues in Asthma Research

Following his remarks, Dr. Panettieri encouraged an open discussion of the hot issues in asthma research. The group was asked to frame their comments as a research question for which a hypothesis could ultimately be developed and tested. The group came up with the following:

- *Why are patients showing up for acute care, but not for chronic care management?*
The group discussed the possible impact of the patient's value system on this issue. When children are doing well, they are doing well. Priority is only given to treating the child when he or she is sick. Another possible difference is a misunderstanding of the use of asthma medications; patients' families may be reluctant to use medicines for fear that their children might become tolerant to them and they may not work when they are really needed.
- *What should be the health maintenance behavior for chronic medical conditions?*
This question attempted to capture some of the previous discussion. The group included in this question the need to define chronic versus acute medical conditions.

- *What are the patient's expectations of primary-care providers?*
The group noted that different patients have different expectations of their primary health-care providers. Some call with every problem; others never do until a situation becomes a crisis. One participant noted that once patients understand that asthma is a chronic disease, they are more likely to come for their well visits.
- *What is the impact of SSI eligibility coverage on asthma rate?*
This issue had a number of subissues, including the fact that SSI families have fewer resources available to address factors contributing to asthma. In addition, these families tend to use the asthma management tools that are covered by SSI funds, such as nebulizers, versus those that are not, such as spacers, even though some of the noncovered tools may be more effective. The group felt there might be a need to research covered vs. non-covered benefits.
- *How many cases of asthma are misdiagnosed?*
The group considered this to be a very important issue and discussed the need to educate primary-care physicians in how to make a correct diagnosis. There was also a discussion about how asthma tends to be misdiagnosed in older children and under diagnosed in younger children because primary-care physicians are reluctant to make a diagnosis of asthma. The group also raised the issue of the consequences of misdiagnosis, e.g., asthma medications being used to treat obstructive sleep apnea can exacerbate this condition due to the side effects of the asthma medications. One participant also raised the problem with managed-care organizations only allowing one inhaler per month, which can promote the misuse of chronic asthma management tools. The group agreed that stronger educational programs, targeted specifically to doctors, school nurses, family members, and the asthma patient, are necessary.
- *What are the valuable outcomes of asthma research?*
Session participants suggested a number of measures including: (1) rates of hospitalization and emergency room visits, (2) quality of life measures, although it was noted that these types of measures have not been validated for inner city, low-income populations, (3) school days missed/parent work days missed, (4) the ratio between the use of corticosteroids and beta-agonists, (5) the secondary costs of health care not associated with asthma but potentially associated with the mismanagement of asthma, and (6) the ability of patients to manage their asthma based on real-life testing of intervention strategies.
- *What is the effect of the influenza and other vaccinations on asthma incidence?*

- *What is the relative value of a medical model for asthma management to an education and prevention model based on innovative strategies (e.g., Pokémon game)?*
One participant discussed the need to empower children to take personal responsibility for managing their asthma. The group recognized the need for user-friendly, educational intervention strategies.
- *How does asthma fit into the individual's overall scheme of problems? How much are people willing to pay in order to manage asthma? How much time are they willing to take, particularly in populations with higher rates?*
- *What are the barriers to an individual's ability to successfully manage asthma?*
- *What is more or less effective in what is being done currently?*
The group discussed the need to integrate programs. Much of what is being done in terms of asthma education and management is fragmented and should be combined into a unified approach. Participants also mentioned the possibility of measuring the cost and value of current educational programs.
- *What are the triggering levels of indoor allergens?*
One participant noted that there is very good research available on dust mites, but not other allergens. Others felt that it was important to understand asthma triggers in order to develop intervention strategies. One group member cautioned that studies to evaluate the effect of eliminating certain triggers must be carefully controlled to avoid the possibility of confusing the effects of strategies to improve asthma management with the effects of remediating certain environmental factors. However, it was noted that intervention studies should be multidimensional.
- *What is the interaction between asthma and the things we regulate, such as outdoor pollutants? What is the interaction between asthma and the things we do not regulate, such as allergens?*
- *What is the mechanism by which asthma is triggered by certain environmental factors?*
- *Is there value to taking down abandoned or partially-abandoned houses?*
This question was raised because children do play in these types of houses, and the possibility exists that families can "live" in them for short periods of time.

- *What is the role of alternative or complementary medicines in the effective management of asthma?*
The group discussed the use of alternative medicine, such as herbs, to treat asthma. One session attendee questioned whether such medicines might actually exacerbate asthma symptoms.
- *Is there value in looking at racial differences with regard to allergy antigen exposure?*
The group noted that evidence exists to suggest that different races have different responses to particular allergens. This points to the need to explore what the mechanisms for this phenomenon are and why it occurs. Participants questioned whether differences in genetic susceptibility coupled with different environmental factors could account for the patterns we see in asthma incidence. One group member mentioned the discovery of gene clusters, which have been linked to different types of asthma, although the cause and effect of this discovery is not known. Another participant noted that these gene clusters have only been identified for certain subgroups of asthma, not for all asthmas.
- *What are the value of prevention strategies, such as breast feeding? Are there preventive strategies that can be taken?*
- *What is the effectiveness, validity, and reliability of asthma screening programs in diagnosing asthma?*
One participant noted that these programs tend to over-diagnose asthma in their attempt not to miss anyone with the disease.
- *Can population-based strategies be developed to measure the effect of eliminating a single environmental factor, such as environmental tobacco smoke? Would such a study be useful?*

3.1.2 Key Research Questions - Summary

At the conclusion of this open-ended brainstorming session, Drs. Lang and Panettieri summarized the issues identified into ten key research questions:

1. What are the differences in health-care delivery systems and their impact on the outcome of asthma care and health maintenance behavior?
2. What are the consequences of misdiagnosing (over-diagnosing or under-diagnosing) asthma in children and adults?
3. What are proper asthma education programs in terms of type, format, and who is providing them? The value of these programs, not only to patients, but also to

health-care providers, should be measured with regard to whether or not the outcomes are valid.

4. What is the value of innovative strategies over medical models of education?
5. How do we identify, understand, and evaluate barriers to successful asthma management?
6. How do asthma triggers interact with the patient? What are the mechanisms?
7. Are there prevention strategies that can be used?
8. What role does alternative/complementary medicine have in asthma management?
9. What is the relationship between differences in racial genetic susceptibility and the effect of environmental factors on asthma?
10. What is the effect of eliminating environmental tobacco smoke on asthma incidence?

3.2 Break-out Session #2: Surveillance: Evaluating the Information Infrastructure

Discussion Leader: *Leslie Boss*, Air Pollution and Respiratory Health Branch, National Center for Environmental Health, Centers for Disease Control and Prevention

Participants in this session included individuals involved in public health protection, clinical care, outreach, and environmental protection. The session focused on the need for improvements to existing ways in which asthma-related data are collected, the types of data collected, and the ways in which such data can be used. The session began with the audience identifying various data concerns and needs. The discussion then turned to an identification of priorities and concluded with a list of recommendations regarding the Information Infrastructure and its role in effectively combating childhood asthma.

3.2.1 Data Concerns and Needs

The group identified data concerns and needs in three broad areas: general data needs, data needs related to children with asthma, and monitoring systems.

General Data Needs

- Medical coverage, insurance, and welfare data - who is getting treatment?

- Hospitalization rates (including readmissions) and emergency room data
- Drug types and their availability to various social brackets
- Types of prescriptions filled to evaluate the balance between the use of drugs to control asthma versus those used to relieve asthma symptoms
- High quality, comparable data from reliable sources
- Local data
- Data on the accuracy of emergency room diagnoses

Data Needs Related to Children with Asthma

- Relationship between the indoor air quality in schools and the incidence of asthma in students
- Relationship between literacy rates and low patient compliance to be examined - are prescriptions being filled?
- Number of children in school that are affected by asthma and the relationship to school absenteeism
- Number of workdays missed by parents caring for asthmatic children
- Number of schools with nurses
- Accessibility to asthma programs and the tools for asthma management (e.g., how many children have peak-flow meters?)
- Data on the sale and distribution of peak-flow meters
- Percentage of schools that allow self-administration of asthma medications

Monitoring Systems

- Need to monitor day care, Head Start, and other similar programs' policies in allowing adults to give asthma treatments to children
- Need to evaluate the positive and negative impacts on regulations relating to environmental tobacco smoke - are there sufficient regulations?

- Need for good databases which are interlinked (e.g., housing, lead prevention) and can be accessed by both individuals with asthma and health providers
- Correlation between hospitalizations and outdoor air quality as measured by air quality codes (green, yellow, orange, red)
- Prevalence in urban/suburban settings and among income levels, which will help determine where resources should go
- Health-care providers need a monitoring system that is easy to use and inexpensive to maintain
- Need to monitor the number of children whose asthma is adequately managed

The group had several discussions about collecting data. One participant noted that existing data are usually generalized and have been collected in a variety of manners. Another group member observed that there had been a lot of discussion about data needs, but very little mention of the data that do exist, with the exception of hospitalization data. There was general agreement within the session that there is a need for high quality data that can be compared among sources. In order to do this, one participant suggested that we needed to know how the data are collected, e.g., insurance/pharmacy companies, phone calls, etc. This led to the recognition that many children with asthma may not be in any system at all, for example, they may not have insurance. The group also agreed that there was a strong need for localized data.

3.2.2 Priorities

A list of priorities emerged from the general list of data concerns and needs. Three main priorities were identified: (1) the need for and collection of new data, (2) the need to better utilize existing data, and (3) the need to make all data more user-friendly.

The Need For and Collection of New Data

- Patterns of care (e.g., patient-specific information which would allow an analysis of trends in the management of the diseases and uncover any potential biases in who receives care and what kind of care they receive).
- Quality of life (e.g., hospitalizations, success of asthma management plans).
- Patient compliance (e.g., patients do or do not fill necessary prescriptions).

- Prevalence of exposure to triggers (e.g., environmental tobacco smoke, outdoor air quality).
- Asthma-related issues in schools (e.g., relationship between asthma and absenteeism both at school and parents' workplace; accurate counts on the number of asthmatic children in school; and number of asthmatic children in school without medications or asthma management tools, such as peak-flow meters and spacers, available).
- Assurance of a single standard for the collection of high quality data (e.g., development of a common case definition of asthma in addition to standardized surveillance approaches).

The Need to Better Utilize Existing Data

- Create a manageable data infrastructure which encompasses multiple elements, such as insurance coverage, place of treatment, etc.
- Create compelling, visual presentations of data using Geographic Information System technology.
- Create a disease registry that involves the whole community, including insurance companies, managed-care organizations, and local health departments.

The Need to Make All Data More User-Friendly

- Data are available but inaccessible.
- The use of a standard definition of asthma will help in making data more comparable.

Participants continued to stress the need for localized, patient-specific data. One group member noted that in addition to aggregate data, such as the number of days of hospitalization per number of asthmatics in the population, there is a need to know where patients are being treated. Several participants also thought it was important to know the impact of insurance coverage on treatment options. One participant also pointed out that localized data would prevent the possibility of wasting resources by treating everybody when only a small segment of the population requires attention.

3.2.3 Recommendations

The group had a number of recommendations.

- Recognize that data needs vary markedly on local, state, and national levels
- Recognize that state health agencies are the focus for asthma surveillance
- Assure political support for asthma surveillance at the state level
- Assure coordination among sources of data (payers, such as insurance companies and Medicaid, and health-care providers)
- Assure the availability of easily-accessible data
- Assure fiscal resources at all levels for:
 - creating a surveillance infrastructure
 - collecting data as needed
 - managing existing data
 - analyzing and disseminating data
- Define and pilot test surveillance techniques; disseminate information about effective techniques
- Plan in advance for data gathering activities to enhance the value and comparability of the data collected; be selective in data requests
- Promote the use of Public Service Announcements

3.2.4 Barriers to Success

Although the group did not specifically address the issue of barriers to success, a number of barriers came up. In terms of the information infrastructure, the two most significant barriers seemed to be resources and the inaccessibility of data. For example, when the need for a disease registry was discussed, one session attendee was concerned about the amount of money that would be required to establish a comprehensive population-based registry. In addition, participants kept returning to the need for accessible data that would reveal information at a local level. Such data could be used to evaluate treatment trends and better target educational programs and treatment options.

3.3 Break-out Session #3: Monitoring Air Quality

Discussion Leaders: *Brent Holben*, Director, Aeronet Network, National Aeronautics and Space Administration
Monica Myers, National Aeronautics and Space Administration

Mr. Holben began this session with a discussion of several NASA technologies that could be useful in the fight against asthma. He focused on satellite- and ground-based remote-sensing technologies that have the ability to capture data on aerosols (which are any particulates), including their type, size, concentration, duration, and location. He spoke more specifically about Aeronet, which is a ground-based, remote-sensing system designed to measure aerosols and explained that NASA has established an Aeronet system at the Maryland Science Center. Mr. Holben then went on to share data collected by that system on the level of aerosols in the Baltimore metropolitan area over the previous 30 days. These data demonstrated increasing and decreasing aerosol levels depending on the ambient weather conditions.

Ms. Myers turned the discussion to the group's charge and asked that participants work to develop five or ten priorities for monitoring air quality and five or ten recommendations for ways to better address this issue. Ms. Myers began the discussion by focusing the group in three areas: (1) tool availability (including those at the Federal and state levels, those that were developed for other uses but may be applied to asthma, and any special data collections that might be necessary), (2) data applications, such as existing bodies of data that might be used to meet a particular need or two or more bodies of data that might be integrated to produce new information, and (3) data accessibility. The group discussed at length this latter topic and participants pointed out that some individual data sets are easily accessible; for example, historical ozone data can be found on EPA's website. One session attendee suggested that a cross-agency resource be established that compiles and tracks air monitoring data from all Federal sources, as well as from state and local sources if possible. Debate then followed about how this could be set up and how it could be accessed through the Internet. Although most of the group's time focused on the issue of data availability, some participants did express their thoughts about the need for outreach to parents, schools, and the health-care community.

3.3.1 Priorities

Group members were then asked to write down their specific priorities and/or recommendations. These ideas fell into three main priority areas: (1) indoor air quality data needs, (2) particulate data needs, and (3) other data needs. Lists of specific needs within each area follow.

Indoor Air Quality Data Needs

- Location: homes, buildings, cars, schools
- Methods for data collection
- Standards for data collection
- Databases
- Information clearinghouse
- Source data, including pet dander, relative humidity, mold, and ventilation in public areas
- Monitoring technologies that are low cost and widely available
- Resources

Particulate Data Needs

- Point source data
- Data on indoor/outdoor levels
- Pollutants, including ozone, particulate matter, and toxics
- Bioaerosols
- Air toxics
- Gridded (2.5 microns)

Other Data Needs

- Data on absenteeism in schools and indoor air quality in schools
- Classroom GIS for asthma topics.

3.3.2 Recommendations

A list of recommendations was also formulated for relating air quality monitoring data to the asthma issue. These recommendations were aimed at addressing the needs previously identified by the group.

Air Quality Monitoring Recommendations

- Development of an indoor air quality database

- Cross-referencing of available Federal data, including links to local and state sources
- Creation of an interagency response unit to provide information to front-line providers of asthma care
- Design of information packages for parents and schools, and asthma education materials based on dialogues with end users to determine their needs
- Initiation of joint Federal projects to develop new technologies, inventory resources, and provide greater opportunities for technology transfer

Other Recommendations

- Develop opportunities for partnering
- Set up a mechanism for providing information to the health-care community and primary health-care providers
- Develop a means for sharing research results within the research community (An e-mail list of session attendees was made for use with a possible asthma and air quality listserve)
- Develop asthma information materials that are highly user-friendly, easy to access (possibly through the Internet), designed to grab the reader's attention, and which present data in a clear and easy-to-understand manner

3.4 Morning Sessions Recap and Report Out Discussion

Moderator: *Elaine Wright*, Deputy Director, Air Protection Division, U.S. Environmental Protection Agency, Region III

This session provided an opportunity for all Conference participants to react to the findings of each of the morning break-out sessions. A representative from each break-out session reported the group's findings and the audience provided additional comments and perspectives. The following is a brief summary of the results of this session.

Break-out Session #1: Science: Setting the Research Agenda for Action

Dr. Lang presented the results of this break-out session. The group identified a number of priority research areas, including:

- Understanding health maintenance behaviors and health-care delivery issues
- Encouraging better asthma diagnosis and education
- Identifying factors which interfere with optimum asthma care management
- Evaluating the effects of eliminating environmental tobacco smoke on asthma incidence
- Improving our understanding of asthma triggers
- Evaluating the effects of alternative/complementary medicines on asthma management
- Determining whether genetic markers combine with environmental factors to influence asthma rates
- Evaluating the reliability of asthma screening programs
- Determining if asthma can be effectively prevented

The discussion that followed this presentation touched on several other research priorities, some of which were global and some of which were specific to Region III. Global research questions included:

- *What works and what does not in training people to provide asthma management?*
Include an evaluation of various alternatives that are being used to provide this kind of training.
- *What is the best mix between environmental controls and medical treatments for alleviating asthma?*
- *What impact do literacy rates, language barriers, and cultural factors have on the perception and management of asthma?*
- *Why is there a lack of patient compliance despite available information?*
- *What are appropriate measures of success?*
Consider the number of days missed from school and workplaces, in addition to emergency room visits.
- *How do we bridge the gap between theory and practice? How do we get people to use the information that exists?*

- *How can we influence health-care provider perceptions of chronic problems (such as bronchitis) vs. asthma in order to improve disease diagnosis?*

The group then focused on issues relevant to Region III:

- *What impact does the mixed climate zone in Region III have on asthma rates? Do moisture-control issues play a role?*
- *What impact do rural conditions, such as lack of electricity and lack of indoor plumbing, have on asthma rates?*
- *What is the impact of HVAC systems in schools and day care centers on children?*

Break-out Session #2: Surveillance: Evaluating the Information Infrastructure

Ms. Boss presented the results of this break-out session. She began her report out with some observations about the session attendees. She noted that of the 41 group members, one-third represented Federal agencies. Only three of the six state health departments were represented, and the majority of non-Federal participants were from Maryland and Pennsylvania. Ms. Boss thought it was important to note that the other states in the Region were under represented; consequently, the group might be biased towards the more urban areas of the Region.

In terms of priorities, Ms. Boss reported that the group had identified three main areas: (1) use of existing data, (2) collection of new data, and (3) development of data that is user-friendly and appropriate. In terms of using existing data, the group identified the following:

- More data are needed; population-based data and patient databases should be better used; and a single standard for high quality data should be developed
- An infrastructure to manage the data should be created
- Data should be presented in creative and visually-compelling ways
- Maximum use of the data should be assured

With regard to collecting new data, the group identified five needs areas: (1) patterns of care, (2) quality of life, (3) patient compliance, (4) prevalence of exposure to triggers, and (5) asthma-related issues relevant to schools.

The group developed several recommendations:

- Recognize that data needs vary markedly on local, state, and Federal levels
- Recognize the state health department as the focus for asthma surveillance
- Assure political support for asthma programs at the state level
- Assure coordination among data sources (such as third party payees)
- Develop a single standard and definition for asthma surveillance
- Assure fiscal resources for a surveillance infrastructure; data collection, as needed; data management; and data use and dissemination at all levels
- Define and pilot-test surveillance techniques and disseminate those that prove effective

The discussion that followed Ms. Boss' report identified several data sources, including the Health Employer Data Information Set (HEDIS) and data from health maintenance organizations (HMOs) on office visits and pharmacy use. The audience also discussed the problem with data "turfism" and the need to break down barriers and encourage the sharing of data to help complete the "big picture" on asthma. There was also a realization that data need to be collected outside of the HMO structure for rural, urban, and transient populations. The group discussion concluded with the observation that data quality objectives are important to developing useful and appropriate data. The objectives of Healthy People 2010 were also mentioned and the fact that this report includes both traditional measures and experimental measures was highlighted.

Break-out Session #3: Monitoring Air Quality

The results of this break-out session were reported by Ms. Myers. The group identified data needs in three areas: (1) indoor air quality, (2) particulates, and (3) other. Indoor air quality data needs included location (schools, homes, additional buildings); sources (mold, relative humidity, pet dander, cockroach infestation, and public space ventilation); methods for data collection; standards for data collection; database development; information clearinghouse and inventory of Federal data; and techniques for monitoring indoor air quality that are inexpensive and widely available. The need for particulate data included: point sources; indoor/outdoor levels; outdoor pollutants such as ozone, particulate matter, and toxics; bioaerosols; air toxins; and gridded 2.5 microns. Other data needs identified included the relationship between school absenteeism and indoor air quality, and the potential application of GIS technology to asthma in the classroom.

The group also made the following recommendations:

- Develop an IAQ database.
- Cross-reference the Federal data; consider creating an inventory of the data that is available, as well as a Federal asthma website with links to state and local sites.
- Create an interagency response unit to serve as a source of information to front-line health providers.
- Ensure that outreach materials are packaged in such a way that they are useful to parents and other users. Create asthma education programs and engage in a dialogue among potential information users to determine how future information should be collected, provided, and used.
- Launch joint Federal initiatives for technology development (SBIR); inventory existing products and equipment; and evaluate which of these may have applications that are transferable to the asthma issue.
- Encourage health-care providers to share their stories of successful asthma interventions.

Partnering opportunities were also discussed by this break-out group. Four areas for potential partnering opportunities were identified: (1) sharing information among health-care providers, (2) sharing research results among researchers, the public, and the Federal response unit, (3) developing outreach materials, and (4) acquiring, building, and/or financing the technologies necessary to collect data and use it effectively in the fight against asthma.

No group discussion followed Ms. Myers' report out.

4. PANEL DISCUSSION: PUBLIC HEALTH PROGRAMS

4.1 National Institutes of Health's Asthma Guidelines

Discussion Leader: *Diane Schmidt*, National Asthma Education and Prevention Program,
National Health, Lung, Blood Institute, National Institutes of Health

Ms. Schmidt discussed the development and content of the National Institutes of Health asthma guidelines. The Expert Panel Report 2, "Guidelines for Diagnosis and Management of Asthma," was released in July 1997 and was the culmination of three years of work by a panel convened by the National Asthma Education and Prevention Program (NAEPP). This report provided basic recommendations for the effective management of asthma. These recommendations were organized around four components:

- Assessing the severity of asthma and monitoring the signs and symptoms and objective measures of lung function
- Avoiding and controlling factors that make asthma worse
- Taking appropriate medications
- Actively involving patients and partners in their own care

Ms. Schmidt stressed that asthma can be controlled by following these basic recommendations, and that the effects of successful asthma management can be seen in reduced hospitalizations and urgent care visits and by a greater ability of patients to enjoy a full range of activities.

Ms. Schmidt next observed that despite what seems like a relatively simple and straightforward approach, asthma is still difficult to control. She then discussed, from a medical management aspect, why this might be the case. In order to be successful, the asthma guidelines must be implemented. The NAEPP has taken a number of steps to encourage the implementation of these guidelines among the medical community. First, the organization has spent great effort in informing health-care providers about the guidelines. Articles have been written, seminars and workshops have been conducted, and education materials and media campaigns have been developed. The NAEPP received feedback from physicians that the guidelines were too long and difficult to understand and that they encouraged a cookbook approach to medicine. Responding to that criticism, the NAEPP condensed their guidelines into more focused recommendations. They also initiated activities to build the skills and confidence within the medical community

necessary to manage asthma successfully. However, despite these efforts, a recent study still suggests that a gap exists between what the doctors say they are doing for their patients and what the patients perceive their doctors are doing. For example, the majority of doctors surveyed said that they discussed the use of peak-flow meters with their patients, and yet only half the asthma patients surveyed indicated that they had even heard of such a device.

Ms. Schmidt then discussed some of the system barriers that NAEPP considered to be affecting the ability of physicians to adequately manage asthma. Among these barriers were the need for: (1) doctors to be allowed more time by managed-care organizations to examine and talk with asthma patients, (2) insurance coverage for educational services, (3) referrals to ancillary providers to assist patients with asthma management, (4) a determination of the effects of formularies on the types of asthma medications prescribed, (5) medical care for the uninsured, (6) referrals to specialists, (7) provisions for children to carry inhalers at school, (8) provisions for school and home remediations, and (9) measures to promote clean air.

To assist in its efforts to have the asthma guidelines implemented, NAEPP has invested in forming partnerships with various organizations to leverage its ability to accomplish this goal. Many of these partners have been at the local level, and NAEPP is now looking to forge partnerships at the Regional level. The organization is also looking to make better use of communication technologies, such as the Internet, to get its message out to the public. Ms. Schmidt concluded her remarks by encouraging each member of the audience to assist in the fight against asthma by informing, building skills, changing institutional barriers, and forming new partnerships.

4.2 Education and Outreach

Discussion Leader: *Linn Manley*, Regional Director, American Lung Association of Pennsylvania - Southeastern Region

Ms. Manley's opened her remarks by giving a brief history of the American Lung Association (ALA) nationally and a description of the Southeastern Region. She went on to explain that four years ago this Region adopted asthma as a core program focus and created an asthma task force to help improve programs and services and to help guide the ALA efforts. Seventy representatives from businesses, organizations, institutions, and hospitals located across a five-county area came together to form Attack Asthma. This group was dedicated to improving asthma care through education, services, and public awareness. Its goals included decreasing hospitalizations and emergency room visits, providing public awareness information about asthma,

increasing the use of prescription anti-inflammatory medications, and decreasing the use and sale of over-the-counter asthma drugs. Seven work groups were formed to address various aspects of the asthma issue: (1) community-based organizations, (2) emergency departments, (3) patient education, (4) pharmacy, (5) primary-care physicians, (6) public awareness, and (7) school, families, and day care. The group believes that by approaching asthma awareness, education, and services at these different levels, they might be able to make an impact on asthma in the community. The kickoff meeting for Attack Asthma was held in September 1998.

Since that time, 90 schools have participated in the “Open Airways” program. Three thousand children in Head Start programs received the Sesame Street “A is for Asthma” program. Nine hundred medical and educational professionals have received some of the Attack Asthma materials.

Ms. Manley then discussed what she considered to be the successes and barriers to the Attack Asthma program. Among the successes that she cited were:

- The group provided a “neutral zone” for an alliance of diverse organizations and individuals seeking a common goal who might not otherwise meet together at the same table.
- The project inspired an effective collaboration among the top experts in the asthma field in Philadelphia, i.e., “the best of the best.” This collaboration served as an impetus to the group.
- The group found open doors for partnerships with community-based organizations with whom they had typically not worked before. This was an important factor in getting the message out to the public.
- The project developed new patient education programs and materials (i.e., What is Asthma?) and expanded available media opportunities through an expansion of services.
- The competition among organizations and institutions to provide the best for their patients and clients served to further the mission of the group and included the need to provide research about asthma.
- Managed-care organizations were supportive of the project’s mission and were cooperative, offering access to their data and helping to implement some of the Attack Asthma programs.

Barriers included:

- Funding
- Data collection and evaluation, i.e., the need to provide the right kind of evaluation and collect the right kind of data to demonstrate accomplishments
- Limited staff allocation
- Initial lack of appropriate educational materials
- Competition in research
- Continuity of members, i.e., the changing faces of health care

Ms. Manley did suggest that this latter barrier could also be considered a success, because bringing different people to the process guaranteed fresh new ideas and constantly expanded the project's network.

Ms. Manley concluded by explaining that the project's steering committee will be meeting in the near future, and that there is a need for some reorganization and expansion of the project, as well as additional funding opportunities.

4.3 Environmental Interventions/Triggers

Discussion Leader: *Douglas Brugge, Ph.D.*, Assistant Professor, Tufts University School of Medicine, Family Medicine and Community Health

Dr. Brugge provided a laundry list of environmental issues that are associated with asthma. He did this so that individuals in the audience could decide which are their priorities and how to integrate them into existing programs. Dr. Brugge divided his list of environmental pollutants into three areas: indoor, ambient pollution, and occupational exposure. Although most of today's concerns about asthma are focused on indoor air quality, Dr. Brugge cautioned the audience not to discount ambient air pollution. Similarly, many chemicals that once were only found in occupational settings are now finding their way into homes.

In terms of ambient air pollution, Dr. Brugge noted that all of the criteria air pollutants regulated by EPA are respiratory irritants (e.g., ozone, sulphur dioxide, particulates, nitrogen oxide and nitrogen dioxide, and air toxics). He shared the results of a study done in Utah of particulate

matter generated by a steel mill located in a valley. During the winter months, the level of particulates rose in the ambient air. This rise was accompanied by a similar rise in asthma admissions to local hospitals. One winter, the steel mill closed down. Not only was there no rise in particulate levels that particular winter, but there was also no increase in asthma-related hospitalizations. Dr. Brugge explained that his point in sharing this study was to help the audience realize that what is outdoors comes indoors and can serve as an asthma trigger.

The body of information regarding occupational exposure is broad, and the concept of single chemical exposure and its association with adult onset asthma has been explored in depth. These studies have generated a long list of occupational chemicals that can create problems; some of these chemicals can be found in homes. Thus the information available concerning ambient air pollution and chemical exposures can help in identifying asthma triggers in the indoor environment.

Dr. Brugge considered both the biological and chemical triggers found indoors. Biological triggers include mold, dust mites, cockroaches, rodents, pets, pollen, and bacterial/respiratory infections. He expressed his particular interest in what affect moisture, which can encourage dust mites, molds, and cockroaches, and the structural conditions of buildings can have on asthma. Looking at potential chemical triggers, Dr. Brugge mentioned environmental tobacco smoke, off-gassing of building materials, carpets, combustion products from stoves and heating elements, household chemicals, and pesticides. Dr. Brugge touched upon the tradeoffs sometimes associated with asthma management, such as the elimination of cockroaches (a potential trigger) by applying a pesticide (also a potential trigger). He recommended that approaches such as integrated pest management be employed to avoid the necessity of such tradeoffs.

Dr. Brugge cited a study of indoor air quality in schools in Sweden. This study found a number of asthma triggers in the school buildings, including cat allergen (tracked in by students), mold, bacteria, volatile organic compounds (VOCs), formaldehyde, and humidity.

In conclusion, Dr. Brugge stated that many sources of asthma exist; it is difficult to decide which to put at the top of the list. He noted that everyone would likely have a different list. Dr. Brugge also stated his belief that there is no smoking gun in terms of asthma--going after only one pollutant, such as environmental tobacco smoke, is not going to work. Multiple environmental exposures will need to be addressed. He observed that this is one key difference between asthma and lead paint. The latter case involved one chemical with multiple exposure routes. Asthma

involves multiple triggers with multiple exposure routes. Thus, Dr. Brugge stated, any solutions to the asthma problem will need to be multi-faceted in nature.

5. AFTERNOON BREAK-OUT SESSIONS

5.1 Break-out Session #1: Education and Outreach

Discussion Leaders: *Susan Jones Sink, RN, BSN, MA*
American Lung Association of Southeastern Pennsylvania
Deb Brown, Delaware American Lung Association

This break-out discussion focused on how to get information to patients and health-care providers. Susan Jones Sink of the American Lung Association of Southeastern Pennsylvania and Deb Brown of the Delaware American Lung Association began the session by making brief presentations on ALA asthma education programs in Pennsylvania and Delaware. Ms. Sink expanded on the earlier discussion of Attack Asthma, an asthma education program targeted to Southeastern Pennsylvania. She described the work of the Attack Asthma education workgroup, the goals of which were to develop curriculum and accompanying materials and to establish a network of lung association volunteers that would actually deliver asthma messages to people in the community. Ms. Sink described the need to distill the NIH asthma guidelines down to what the “man on the street” needs to know about asthma. To do this, ALA developed a 30-minute course designed to educate patients so that they would be able have informed talks with their physicians about managing their asthma. In order to get this course in the hands of as many people as possible, ALA decided to identify a group of people that they could train who would then go into the community and train others. Initially, 40 people were trained, including church and community leaders. Within 12 months, 950 people had attended groups that utilized the Attack Asthma curriculum.

Ms. Sink described what she considered to be the major successes and failures of the program. The program did successfully get the Attack Asthma curriculum into the community. The materials that were developed to support the course were excellent and have been widely accepted across the nation. A great deal of effort was put into developing these materials so that they could be understood by everyone, including those with a low literacy rate; they were, therefore, written at a third-grade reading level. However, the program failed to realize that information about asthma did not lend itself to a “Basic Life Support” model (i.e., a set of easy to understand messages that could be taught to a variety of audiences). Asthma information is highly technical, complex, and individualized. People who attended the courses had a vested interest in the subject, either having asthma themselves or having children or other family members with it. Consequently, the questions that were asked were highly sophisticated and

often overwhelmed the volunteer trainers. It was soon recognized that the training could only be given by health-care professionals or individuals thoroughly trained in the various aspects of asthma.

The second program Ms. Sink described was ALA's "Open Airways" program for schools. This program is based on a six-session curriculum designed to teach children between the ages of eight and 11 how to manage their asthma. ALA's goal is to make this curriculum available to every elementary school in the United States.

Ms. Brown told the group that the Delaware ALA, which had existed for less than a year, had a similar Attack Asthma program. Their program was comprised of six committees, similar to those utilized in Southeastern Pennsylvania. The Delaware ALA uses the "Open Airways" and the "A is for Asthma" programs. In addition, the largest hospital in the area also offers an asthma education program. Ms. Brown talked about how the ALA is partnering with various community groups, and she stressed the relationship that they have enjoyed with the religious community. Churches have a strong interest in playing a role in educating their congregations about asthma. Similarly, employers have also been strong partners, seeking to educate their employees in an effort to control medical costs. Ms. Brown also mentioned the strong partnership they have with school nurses and their importance to the Delaware program. Every school in Delaware has a school nurse and ALA recently supplied each one with a nebulizer to ensure that asthma treatments are provided for students, as needed, during the school day.

5.1.1 Issues to be Addressed

Following these presentations, the group turned to a general discussion of asthma education and outreach. As discussion progressed, the group developed a list of issues that need to be addressed, including:

- *How do we teach child care providers to properly administer asthma medication to young children? Young children cannot be responsible for their own medications.*
- *How do we improve communication between health-care providers, insurance companies, and patients?*
- *How do we identify persons within managed-care organizations who can provide individual help in resolving issues specific to a particular case, e.g., coverage for*

non-formulary medications or asthma management tools?

- *How do we specialize case management for those who do not “fit the mold?”*
- *How do we establish partnerships within the community to train volunteers to assist with providing asthma education in order to free doctors up to spend more time with patients requiring special attention?*
- *How do we educate teachers about managed asthma care so that they can help, rather than potentially interfere with, children in the management of their asthma?*

5.1.2 Priorities and Recommendations

Based on these issues, the group created a list of priorities and recommendations aimed at better educating health-care providers, insurers, employers, parents, and children about managing asthma. These suggestions fall into three main topic areas: (1) health-care services, including medications and tools, (2) educational services, and (3) coordination of activities and data collection.

Health-Care Services

- Teach child-care providers how to administer asthma medication to those too young to do it themselves
- Make equipment, such as peak-flow meters and spacers, readily available, and encourage insurance plans to cover their cost and allow them to be distributed through physicians’ offices
- Work locally with Medicaid to provide equipment, such as peak-flow meters and spacers (In certain communities, Medicaid is the primary source of health-care coverage)
- Establish mechanisms, with both insurance providers and medical professionals, to treat patients requiring specialized care
- Ensure that intermittent asthmatics receive adequate asthma education. They are the least likely to get it, and consequently may end up in a high risk category.

Educational Services

- Provide financial incentives for health-care providers to better educate patients, i.e., reimburse doctors for their time spent in educational activities
- Develop better tools and materials to help doctors educate patients within the constraints of the typical physician's office that is working with a dozen or more insurance manuals
- Help managed-care organizations provide educational incentives
- Encourage parents to become actively involved in managing their child's asthma
- Create a task force for standardizing the teaching and certification of asthma educational trainers
- Develop more user-friendly tools and visual materials for young children
- Educate teachers and other school officials about managing asthma
- Create a standard of minimum education given to all asthma patients

Coordination of Activities and Data Collection

- Encourage health-care providers to communicate more
- Provide a link between managed-care providers and partnership networks
- Help managed-care organizations better coordinate the information they provide to physicians concerning asthma
- Establish partnerships with doctors specifically for asthma education
- Improve coordination between groups such as Healthy Child Care America and other groups in each state, such as ALA, Head Start, etc. Not only will this prevent a duplication of efforts, it will also keep these groups from competing with each other for the same small pot of grant money.
- Use child-care providers to help gather data (e.g., number of days of school missed, etc.)

Several other issues were raised by the group. Several group members wondered how physicians' behavior could be changed with regard to educating patients about asthma. It was suggested that

before this could be done, there would need to be a better understanding of what went on in a physician's office. Another participant suggested the need for a model for comprehensive care; this would provide the basis for everybody in the community doing the same thing or at least sharing a common understanding of the asthma issue. Lastly, the group discussed the barriers to gaining information from schools about their students with asthma. This can seriously limit the ability to evaluate the success of programs, such as Open Airways, in terms of improving asthma management using measures such as school absenteeism.

5.2 Break-out Session #2: Health-care Interventions

Discussion Leader: *Tyra Bryant-Stephens, M.D.*, Medical Director, Community Asthma Prevention Program, Primary Care Center at University City, The Children's Hospital of Philadelphia

Dr. Bryant-Stephens opened this session with a description of the Community Asthma Program she operates in Philadelphia. She explained that the goal of the Community Asthma Program is to erase the discrepancy between the amount of medications available and the continued increase in asthma morbidity and mortality. Dr. Bryant-Stephens noted that at the same time that our medications are becoming more effective and available, asthma morbidity and mortality are on the rise. This phenomenon is counterintuitive, and Dr. Bryant-Stephen's program seeks to reverse the trend through intervention in patients' homes.

The Community Asthma Program is implemented throughout West Philadelphia and uses a three-prong approach: (1) community education classes, (2) the Home Intervention Study program, and (3) a "train the trainers" program. The community classes are designed to educate parents and children about asthma and asthma-related issues. They consist of five weekly classes; children and parents attend classes at the same time, although they are in different class rooms. The classes are peer-facilitated and are conducted in a very informal atmosphere. Incentives, such as mattress covers, gift certificates, and "asthma packs" (peak-flow meters, spacers, etc.) are offered to promote regular class attendance. Dr. Bryant-Stephens was very excited about the success of these classes - follow-up with class attendees indicates a retention rate of between 80 and 85 percent of the information presented. The "train the trainers" program takes highly motivated parents and provides them with two weeks of additional training. Once they are approved by the Program director, they are then allowed to go out and teach asthma education on their own.

The objective of the Home Intervention Study program is to determine if environmental

interventions in the homes of moderate to severe and persistent asthmatics can change the outcome of their disease and lead to a better quality of life. Home intervention aims to eliminate triggers such as cockroaches, pets, dust mites, mold, and ETS. The following participant criteria are used:

- Individuals must be at least two years of age
- Individuals must belong to one of the primary-care centers of the Children's Hospital of Philadelphia (to allow easy access to their medical records)
- In the past year, individuals must have had one or more hospitalizations OR two or more asthma-related emergency room visits OR two or more visits to a primary-care center for asthma exacerbations. Patient charts are audited to determine whether the patient exhibits moderate to severe asthmatic conditions.

Individuals are broken down in the three age groups: (1) two to three years of age, (2) three to five years of age, and (3) five to sixteen years of age. The majority of study participants are in this latter group. In addition, these groups are further broken into a control group and an intervention group. Participants in the control group are asked to do the following:

- Keep a diary of symptoms, both day and night, as well as medication use
- Attend community asthma-education classes
- Keep all routine appointments with the primary-care physician
- Complete all Study questionnaires

In addition to these four things, participants in the intervention study can expect visits from a home visitor. This lay individual goes into the home and evaluates the child's bedroom for potential asthma triggers. Interventions are initiated based on this assessment and follow-up visits are conducted twice monthly to ensure continued maintenance of these intervention strategies.

The Study has adopted the following outcome measures:

- Hospitalizations and emergency room visits
- Missed school days/parent work days
- Use of beta-agonists (rescue medications)
- Number of unscheduled visits to the primary-care physician
- Quality of life measures that have been developed for this population group

The types of interventions that have been made to date include: (1) floor repair or replacement of carpet with tile, (2) provision of vacuum cleaners, (3) wall repair and/or painting, (4) roach and

mice baiting, (5) professional pest control for cases of severe cockroach infestations, (6) provision of hypoallergenic mattress covers, new pillows, pillow covers, storage bins, bookcases, and shades, and (7) the washing of baseboards with buckets of water and mops. Some of the hurdles that have been encountered include:

- Missed appointments (the home visitor usually schedules three appointments for every one that is kept)
- Costly repairs
- Decreasing interest, particularly on the part of the control group
- Inability to make a difference in only one home visit (at least three visits are usually required to complete the intervention)
- Difficulty in tracking the use of beta-agonist medications based on refills from emergency room and physician visits
- Optimization of medication management (audits of medical charts revealed that medications prescribed are not necessarily found at the homes)
- Ability to keep the home visitors' records up to date
- Welfare restrictions
- Declining attendance in education classes, although some new incentives, such as movie tickets, are being introduced

Dr. Bryant-Stephens wrapped up her presentation with a discussion of the Program's status. She stated that 130 families are now enrolled in the Program, which is just reaching its one-year mark. However, she noted that it is too early to look at outcomes in terms of asthma morbidity markers; results will be more meaningful after two years. Dr. Bryant-Stephens also shared with the group several of the forms used by the Program and the types of data collected.

The group had a number of questions about the Community Asthma Program. Questions and concerns pertaining to various subjects such as funding, how a home visitor obtains assessment form information, and the applicability of HEPA filters to alleviate environmental triggers came up during the discussion. Dr. Bryant-Stephens explained that her goals for this year included training health-care providers, enhancing funding, increasing the number of families enrolled in the study, and ensuring regular follow-up after interventions have been completed. She also mentioned that

she is trying to partner with pharmaceutical companies in the area to expand the availability of education resources. When asked about follow-up and retention rates, Dr. Bryant-Stephens explained that telephone calls were made after three months, six months and one year in the program to participants to gauge their retention rates. The group also wondered how landlords felt about the home-intervention program, and Dr. Bryant-Stephens responded that it depended entirely on the individual landlord - some are grateful, others are upset by the process. She also explained that many of the houses that they deal with in the context of the Home Intervention Study are not project or public housing; instead, they are very old, individually-owned houses.

5.2.1 Recommendations

Following the discussion about the Community Asthma Program, Dr. Bryant-Stephens refocused the group and developed a list of recommendations in terms of where health-care interventions can occur. Five areas of opportunity were identified: (1) primary care, (2) community, (3) school, (4) home, and (5) emergency room. Specific recommendations by the group follow:

Primary Care

- Provide one-on-one training to physicians and their staffs
- Call social services if you know that parents are not using nebulizers when necessary
- Create better partnerships between the medical community and school nurses
- Use an asthma triage form so that nurses can determine whether a child should be seen in the office or go to the emergency room
- Notify primary-care physicians and specialists when one of their patients is seen in the emergency room
- Use a standardized form in the chart of each asthmatic child which reminds doctors to ask certain questions and evaluate certain health indicators
- Promote smoking cessation programs (this was considered to be applicable to all areas)

Community

- Make better use of churches, after school programs, and day care centers to

deliver asthma education

- Provide asthma education to foster homes
- Educate pharmacists about the proper use of asthma medications and devices, as well as providing patients with information on accessing devices, such as peak-flow meters and spacers

School

- Train physical education teachers and other school personnel about asthma and how to care for it
- Work to gain exemptions for asthmatic students from policies regarding medications on school campuses (asthmatics are not carrying their inhalers at school because of a fear of being expelled)

Home

- Promote better smoking cessation efforts and removal of other asthma triggers in the child's environment
- Obtain parental permission to allow the child's medical information to be sent directly from the primary-care physician to the school nurse who can help with a child's asthma management plan

Emergency Room

- Encourage patients to use their primary-care physicians for asthma exacerbations rather than going to the emergency room
- Make sure that patients have a connection with a primary-care physician

5.3 Break-out Session #3: Environmental Interventions

Discussion Leaders: *Mark Heil*, Indoor Environments Division,
U.S. Environmental Protection Agency
Jerold Aronson, M.D., M.P.H., FAAP, American Academy of Pediatrics

Mr. Heil opened the session by describing EPA's approach to environmental controls for asthma. He explained that EPA has adopted a three-pronged approach that targets the medical and health-care communities, schools, and parents to make them aware of the significance that indoor factors can play in asthma. Key indoor asthma triggers include environmental tobacco smoke (ETS), dust mites, pets, and molds. The National Academy of Sciences will issue a report in December summarizing the current science with regard to asthma triggers and potential mitigation strategies.

Mr. Heil then discussed EPA's outreach efforts, which include conducting a national media campaign on asthma and environmental tobacco smoke, providing grants to state tobacco control programs to add an educational component on environmental tobacco smoke, and using a network of over 900 community-based organizations to reach parents and children. Efforts to reach the medical and health-care communities include an economic analysis of the benefits of indoor environmental management, an assessment of managed-care practices and coverage related to smoking and ETS, and the education of pediatric and public health officials on the health problems associated with ETS. School outreach efforts include hands-on education of children, education of school nurses, and the implementation of good indoor air quality practices through the use of EPA's "IAQ Tools for Schools" program. EPA also has a pilot program to incorporate good indoor air quality practices into day care settings.

Dr. Aronson then described to the group the "Clean Air for Healthy Children" program. This initiative works to ensure that health-care providers are able to effectively counsel their patients on smoking cessation issues. Dr. Aronson discussed the impact that environmental tobacco smoke has on asthmatic children and explained that smoking cessation counseling as brief as three minutes can make a difference. Health-care providers are trained using the "Breaking the Chains" teaching module and are taught a number of brief counseling strategies. In describing this program, Dr. Aronson touched upon the objectives of smoking cessation counseling, the process that people go through to change their behavior, and the need for follow up to prevent smokers who have quit from relapsing. Dr. Aronson also stressed the need to mobilize the health-care community to adopt this approach. Through widespread smoking cessation counseling, Dr. Aronson believes that we will be able to positively impact the health of up to 40 percent of the

asthmatic children exposed to environmental tobacco smoke in their homes.

5.3.1 Priorities

Following these opening remarks, the group turned its attention to determining broad areas of priorities and needs. Six were identified:

- Housing conditions
- Schools
- Environmental Tobacco Smoke
- Ambient pollution
- Occupational exposure
- Legislation

Expanding on these needs, the group focused on more specific priorities. In the area of housing, the group identified the need for an inventory of housing stock at the state level (i.e., the number of trailers, apartments, single-family homes, etc.). Participants also wanted guidance on effective, holistic, and realistic interventions. Too often guidelines are not practical for people to implement on a daily basis or they are not suited to rural or urban conditions. In terms of schools, the group wanted to see better and broader enforcement of smoking bans. This included extending bans to encompass whole campuses, including teacher lounges. Several group members suggested carpet guidelines for schools and public housing, as well as guidelines for the use of pesticides in a variety of buildings, including schools and malls. The group also recognized the need to provide school professionals with the education necessary to make school environments healthier and to allow for or assist students with the use of asthma medications on campus.

The group was very concerned about environmental tobacco smoke. They wanted to see the adoption of standard guidelines on ETS. Participants also believed that there is a need to develop Federal guidelines on managed-care coverage for asthma-related services and they wanted to see more HMO funding for services such as smoking cessation programs or extended physician counseling. The group felt that the Health Care Financing Administration should be involved in efforts to include asthma medical devices and medications in managed-care benefits.

From a legislative perspective, the group wanted to see more smoking bans in public spaces, thus removing ETS from these areas altogether. They also felt that there should be legislative initiatives to increase funding for promoting good IAQ practices in public buildings. In addition, funding to research the dose relationships of indoor pollutants other than ETS should be sought.

A variety of other issues were raised. The group was very interested in HMO support and coverage of environmental management of asthma triggers. They believed there is a need to better establish the role of ambient pollution as an environmental trigger. They also suggested an increased focus on occupational triggers since these now have the potential to impact homes.

Two overarching themes emerged from the group discussion. First is the idea that a holistic approach is a necessary element of environmental interventions. The group was in agreement that from an environmental perspective, asthma cannot be effectively treated simply by removing one trigger. Environmental interventions must incorporate all triggers. Secondly, the group expressed the need for background research and data on the effects of environmental triggers on asthma. Hard data are necessary to bring about legislative change. The group observed that legislators, health-care providers, school officials, and parents often require hard evidence on the effects of environmental triggers on asthma before they will take any action.

5.4 Afternoon Sessions Recap and Report Out Discussion

Moderator: *Elaine Wright*, Deputy Director, Air Protection Division, U.S. Environmental Protection Agency, Region III

This session provided a recap of the afternoon break-out sessions and the opportunity for the whole group to react to the findings. As in the morning recap session, a representative from each break-out session reported the group's findings and the audience provided additional comments and perspectives. The following is a brief summary of the results of this session.

Break-out Session #1: Education and Outreach

Ms. Sink presented the following priorities/needs:

- Coordinate activities with organizations such as Healthy Child Care America and the American Association of Pediatrics
- Teach child care providers how to administer asthma medication
- Use child care providers to gather relevant data, such as days absent
- Ensure the ready availability of peak-flow meters and spacers and their coverage by insurance providers
- Encourage managed-care organizations to establish liaisons to serve as trouble

shooters or to provide specialized case management

- Work locally with Medicaid to provide peak-flow meters and spacers
- Encourage providers to communicate
- Keep in mind that some patients need individualized case management
- Educate members and physicians to link HMOs to network
- Provide incentives for physicians to offer asthma education
- Develop good tools for physicians to use, within the constraints of their offices, to offer asthma education
- Encourage managed-care organizations to coordinate their tools and their educational incentives
- Encourage parent buy-in to the concept that asthma is a chronic disease that requires comprehensive care
- Establish local coalitions and task forces for standardized teaching and develop national asthma certification
- Develop user-friendly tools and visuals (i.e., videos) to teach young children about asthma and its management
- Create partnerships with doctors for education
- Educate teachers about asthma and how to take care of it
- Create a minimum education standard for all asthma patients and administer some sort of evaluation that physicians could give their patients to ascertain their competency
- Encourage involvement with the faith community to deliver asthma education

The audience shared two other ideas. The first concerned the establishment of a “Good Samaritan” policy, which would allow people to help asthmatic children without fear of litigation. The second concerned the need to not only educate children and parents about asthma when they are first diagnosed, but also to continue the process of reeducating them as often as necessary.

Break-out Session #2: Health-care Interventions

The recommendations of this break-out session fell into five areas: (1) primary care, (2) home, (3) community, (4) school, and (5) the emergency room. Dr. Bryant-Stephens discussed the priorities in each area:

Primary Care

- Promote appropriate medical management of asthma using the available guidelines
- Use peer counselors/educators for providers and primary-care staff
- Use interactive teleconferencing for continuing education
- Encourage HMOs to identify the prescribing practices of differing physicians to promote better ratios between the use of preventive and rescue medications
- Encourage parent-driven advocacy
- Refer cases of medical neglect to child services
- Provide formal notification to primary-care physicians, specialists, and school nurses of emergency room visits and hospitalizations

Home

- Enhance smoking cessation efforts
- If possible, go into homes and remove environmental triggers, particularly in the patient's bedroom

Community

- Use lay community workers to go into homes to remove environmental triggers
- Work with family centers to educate the community about asthma and possible interventions
- Conduct pharmacy education about asthma medications and access to asthma devices

School

- Train school nurses
- Partner with schools for education programs
- Improve school policies that limit carrying asthma medications
- Educate the support staff in schools that may be required to administer medications or respond to emergencies

The Emergency Room

- Promote interventions to connect patients with their primary-care physicians; encourage patients to use their primary-care physicians rather than going to the emergency room

The audience had several comments. They were very supportive of the idea of training school nurses and recommended that school personnel advocate for better indoor air quality in schools. They also suggested that schools use EPA's "IAQ Tools for Schools" to help them identify possible triggers. One participant questioned whether emergency medical technicians are trained in asthma management. Another audience member commented that some paramedics have pediatric training (PALs). The group also noted that certified respiratory therapists in Maryland conduct asthma education and suggested that this might be a national resource that could be tapped.

There was also a discussion about the confusion that many patients have between asthma control and rescue devices and medications. The group wanted these medicines to be made easier to distinguish. Several suggestions for how to do so were offered, including color-coding and shape differences. One participant suggested approaching the pharmaceutical companies in Region III on this topic.

The group also discussed the concern that school officials have about medications on campus. For example, no Baltimore student may have medications on his or her person while at school. A policy is now being written, which will be presented to the school board, to exempt inhalers from this prohibition. There is also some state legislation on this topic. Finally, a concern was raised about the possibility that there may be no one at a school, such as a nurse or trainee, that would be available to handle an asthma crisis. It was suggested that the ratios between school nurses and number of students be examined.

Break-out Session #3: Environmental Interventions

Mr. Heil reported out for this group, which identified five priority areas: (1) housing conditions, (2) schools, (3) environmental tobacco smoke, (4) legislation, and (5) others. The group had the following recommendations for each topic area:

Housing Conditions

- Data should be available on the type and quality of housing stock in the United States.; this would allow more targeted interventions
- Guidance is needed on effective, realistic interventions using a holistic approach to reduce exposure to environmental triggers; care should be taken not to recommend actions that are difficult or expensive

Schools

- Enforce smoking bans
- Bans should include all school property, including buses
- School interventions should be holistic and include not only an evaluation of the physical environment, but also training for school nurses and administrators; particular care should be given to the use of pesticides

Environmental Tobacco Smoke

- Implement the Agency for Health Care Policy and Research (AHCPR) guidelines
- Teach best practices for smoking cessation at teaching hospitals; supplement the training that medical students receive at medical school concerning smoking cessation
- Include the Health Care Financing Administration in asthma-related work
- Provide Federal guidance on the coverage of smoking cessation programs which will encourage their use
- Encourage HMOs to fund smoking cessation programs

Legislation

- Enact smoking bans in public places

- Promote good indoor air quality by adequately funding IAQ management practices in public buildings, e.g., schools, to prevent their deterioration

Other

- Encourage HMO support and coverage of environmental management of asthma
- Remember the role of ambient pollution
- Pay attention to occupational asthma
- Provide guidance on carpet

The group added several recommendations:

- Provide legislation for research needs in the area of dose response
- Enforce building ventilation codes in public buildings, e.g., implicit regulations of ETS in multi-family buildings
- Design environmental intervention strategies to address multiple triggers
- Promote the use of cigarette taxes
- Work with regional transportation departments to minimize the impact of roadwork on pollution levels

DAY TWO
November 19, 1999

6. DISPROPORTIONATE IMPACT: ASTHMA IMPACT ON POOR AND MINORITIES

6.1 *John Groopman, Ph.D., Chair, Department of Environmental Health Sciences, School of Hygiene and Public Health, Johns Hopkins University*

Dr. Groopman opened this panel discussion by observing that the poor and minority populations in this country are disproportionately impacted by every chronic disease, whether it be asthma, diabetes, or something else. In addition, individuals who are afflicted with asthma are also at increased risk for virtually every other chronic human disease. Eventually, Dr. Groopman hoped that we may be able to more comprehensively tackle these types of problems as an overall public health issue. With that thought, Dr. Groopman introduced the first panelist, Mr. Mark Brennan of the U.S. Department of Transportation's Office of Civil Rights.

6.2 *Mark Brennan, Office of Civil Rights, U.S. Department of Transportation*

Mr. Brennan opened his discussion by stating that the transportation infrastructure is often accused of contributing greatly to the asthma epidemic among the African American and Hispanic populations residing in America's cities. The approach taken to this problem by the Department of Transportation (DOT) is somewhat fragmented because of the very nature of the Department. DOT regulates almost anything that rolls, glides, flies, or floats in the United States. Thus, the Department has a very strong interest in both environmental issues, as well as civil rights issues. DOT's regulatory approach is founded on various statutes, such as the Clean Air Act, Title 6 of the Civil Rights Act of 1964 (which prohibits discrimination on the basis of race, color, or national origin), the National Environmental Policy Act (NEPA), and the President's Environmental Justice Executive Order.

DOT also has its own environmental justice order within the Department, which requires personnel to do what they can to eliminate, prevent, and remediate substantially high and disproportionate adverse effects of transportation projects and planning on minority and low-income populations. It is especially difficult to address low income populations from a regulatory standpoint, since no statutes exist in this country which prohibit discrimination on the basis of income. But in many cases, especially in America's cities, African American and Hispanic racial ethnic status is a proxy measure for a population with a high percentage of low-income residents.

Because of this, DOT's anti-discrimination regulations do reach a lot of protected populations.

Nevertheless, the Department does receive a fair number of allegations and administrative civil rights complaints alleging that mobile sources of air pollution are causing the epidemic of childhood asthma among African American and Hispanic children in the nation's cities. When these allegations are repeated to people in the Department who work on Clean Air Act issues, they suggest that this is a scientific impossibility, because emissions from vehicles are going down, while the incidence of childhood asthma is going up. They question the causality.

Although Mr. Brennan is not an epidemiologist, he suggested that it is difficult to tease out causality in epidemiology. He felt that demonstrating a causal link would be a little easier from a civil rights point of view, as those who study the issue are not held to the strict scientific standards of risk assessment. Instead, the "disparate impact standard" under the civil rights laws requires that to show discrimination, one must make his or her case by a preponderance of evidence. This is a simple weighing procedure that says the material evidence on one side is more persuasive than the material evidence on the other.

DOT considers the transportation infrastructure system as going beyond mobile sources (i.e., vehicles or other things that move around) to include the activities related to removing the fuel from the ground, transporting fuel sources to refineries, refining the fuel, transporting it to gas stations, and pumping it into cars. Another issue, which Mr. Brennan felt needed more focus, is particulate emissions--not necessarily emissions from the burning or leaking of fuels, but rather those resulting from road or automotive wear (i.e., pieces of tires or brake shoes). Such emissions are known as fugitive dust.

Research performed by Mr. Brennan to determine what the Department's contribution is or is not related to the asthma epidemic suggests that there are as many theories of the causality of the asthma epidemic as there are researchers. Mr. Brennan related a story which had to do with a freighter full of soy powder that was docked in the Port of New Orleans a number of years ago. There was a strong wind storm and the hatch covers on the freighter were loose and allowed soy powder to be blown across an African American neighborhood in New Orleans. For two or three days after this incidence, the number of emergency room visits and hospital admissions for asthma spiked, although the causality was not clear.

DOT does try to drive down pollution. Cars are a lot cleaner -- each individual car emits far less

pollution now than it used to, but the number of vehicle miles traveled continues to increase. Even though each individual car might pollute less, therefore, the number of vehicles on the road keeps rising. DOT is developing some high-tech strategies like intelligent transportation systems which are trying to reduce congestion. The Department knows that traffic congestion causes more pollution – cars stopping and starting produce more pollution than cars moving smoothly down the road. DOT is also working on some low-tech solutions, particularly in the area of particulate emissions. Simple things like filling pot holes, paving roads, and using disc brakes instead of brake shoes reduce the amount of particulates in the air.

The Department also hears that diesel trucks and buses are particularly offensive to minority communities and that there is a push for studies of alternate fuels. One of the problems with diesel is that it produces more particulates than gasoline. So if particulates are an asthma trigger, this could help explain the objection to the continued use of diesels. The particular effects in terms of the African American and Hispanic communities might hypothetically come about in part because of housing segregation. In other words, if lower-income minority communities are located in close proximity to railroad tracks, they would experience a greater incidence of particulate exposure because trains burn diesel fuel.

DOT has two processes by which these types of issues reach it legally: through the administrative complaint process and through law suits filed under the Clean Air Act. Private citizens and advocacy groups can file complaints and law suits under the Clean Air Act. In addressing such issues, DOT supports the development of regional and metropolitan solutions to transportation and air pollution problems. As an example, Mr. Brennan discussed a large, ongoing project in the Atlanta metropolitan area, in which DOT is attempting to bring all parties to the transportation infrastructure and the governing bodies in the Atlanta metro area together to develop solutions to Atlanta's overall transportation problems. Atlanta is a nonattainment area under the Clean Air Act, which means that it exceeds certain guidelines for air pollution.

Throughout the country, there are Metropolitan Planning Organizations (MPOs) which are responsible for developing and implementing metropolitan or regional transportation plans. In addition to planning the surface transportation infrastructure for these metropolitan areas, the MPOs are to come up with plans and inputs to correct the nonattainment of air pollution goals under the Clean Air Act. They are only supposed to engage in activities that will make the air cleaner in metropolitan areas. There are a lot of ways that this can be accomplished: increasing the availability and use of mass transit, implementing high occupancy vehicle lanes, encouraging

van pooling, and having people live closer to their jobs. DOT is trying to work with more and more of these MPOs to gain a bigger focus on what issues exist from a legal point of view as an environmental justice issue; from an environmental point of view as a Clean Air Act issue; and from the public's perspective as a health issue.

DOT feels that it is making good progress in Atlanta. There are some other areas that the Department is working in as well, but it is very difficult to model from a conceptual or analytical perspective what is happening in these metropolitan areas. Because these areas are highly congested and often utilize complex traffic patterns, the number of potential variables prohibits the use of modeling techniques in developing solutions. However, DOT does feel that the Atlanta project will have a lot of benefits which will be applicable in addressing transportation issues in other metropolitan areas.

In closing his remarks, Mr. Brennan indicated that DOT is publishing new regulations under NEPA which will require consideration of socioeconomic implications in environmental impact statements. The regulations will explicitly include requirements for consideration of environmental justice for the first time; NEPA currently only mentions socioeconomic impacts in passing, but does not identify specific compliance requirements. DOT has also issued guidance to its MPOs to explicitly include civil rights considerations. DOT feels that it is moving in the right direction, although it recognizes that the transportation infrastructure, to an unknown extent, is probably contributing to the childhood asthma epidemic.

A member of the audience raised the issue of cross-jurisdictional air pollution and asked how it is being addressed at DOT. Mr. Brennan indicated that some MPOs do cross state lines and that their planning is supposed to have a regional focus. He also admitted that this can be difficult at times, because the Federal Highway Administration is geared towards individual states.

Another question was asked about whether the health status of a community was taken into consideration during the decision-making process of transportation planning. Mr. Brennan answered that it was not taken into consideration sufficiently. To address this concern, DOT has been trying to emphasize public participation. He went on to explain that there are a lot of regulations that require the needs and views of minority and low-income populations to be solicited and considered. But the public participation model has not been invoked sufficiently. Consequently, DOT is pressing on the state departments of transportation and on the MPOs to improve and expand the public participation process, so that the views of minority and low-

income communities can be considered much more seriously and much earlier in the process.

He also explained that DOT is trying to push for an inventory of the transportation needs of a community. Once this inventory is completed, it can be compared to the existing transportation infrastructure and gaps can be filled. Mr. Brennan admitted that it has been difficult for DOT to get state departments of transportation to talk to state departments of health and human services and state health departments. It has been a weakness in the process. Mr. Brennan observed that, even if DOT succeeds in getting transportation planners on the regional and state level to listen to low-income and minority groups, it still will not necessarily be getting the input of health experts in terms of the health status or condition of a community.

6.3 *Dianne Demers, PA-C, CLU, Minnie Hamilton Health Care Center, Inc., Calhoun County, West Virginia*

Ms. Demers is a physician's assistant in a small, rural county. 8,000 people live in the county and she works in a school-based health clinic. Her office is in the middle/high school, which serves grades 5-12. She has two exam rooms and a conference room for mental health services. Being located in a school allows her to do a lot more follow-up than might be done in a private physician's office.

Before Ms. Demers came to West Virginia, she worked in North Carolina, where she worked in a county health department that had a pediatric practice of about 6,000 patients. At that time, she knew nothing about asthma, but she worked with a nurse practitioner who had 17 years of pediatric experience, including three years in pulmonology. It was under the supervision and instruction of that nurse practitioner that Ms. Demers learned how to use nebulizers and how to teach parents to use nebulizers. Because half of the population was Mexican and spoke no English, Ms. Demers had the added challenge of working through interpreters to teach parents and students the basics of asthma care and treatment. Ms. Demers felt that the clinic was extremely aggressive in their asthma program. It brought nebulizers to patients seven or eight times a day; peak-flow meters were also used daily. Out of 6,000 patients, only one student was hospitalized for asthma.

Ms. Demers left North Carolina and returned to West Virginia where she was trained. The new clinic in which she worked had a very different approach to asthma. For example, the first patient she saw, Ms. Demers thought had asthma. When she asked the staff where the nebulizer machines were kept, she was given the name of a company to contact which would deliver one to

the parents. This seemed somewhat impractical, since some of the houses in the community were three miles down a hollow. This arrangement also meant that Ms. Demers could not provide any instruction to the student or parents on the use of the machine. When she asked where the peak-flow meters were kept, staff brought her a box that contained a metal cylinder with a plastic disposable tube. When it was blown into, a metal pipe came out the end. Ms. Demers was shocked by the contrast between the two clinics.

When Ms. Demers introduced herself to the pharmacists in town, she discovered that they did not stock peak-flow meters because nobody used them, and they could not remember the last time anyone ordered one. Then she started to see kids, and the typical story told by parents was, “My seven year old Johnny gets bronchitis three times a winter – we need an antibiotic right away.” However, in examining “Johnny,” Ms. Demers determined that he didn’t need an antibiotic – he needed an inhaler. So, she started prescribing inhalers.

However, patients were not always receptive to using inhalers. The typical story she heard from students and parents is that they cannot be taught how to use inhalers. They will not use anything except antibiotics, and if she does not prescribe them, then they go away angry. However, Ms. Demers told the group that she continues to prescribe inhalers. The pharmacists have told her that she is the only one prescribing inhalers. Some parents are willing to listen and put their child on an inhaler, but when the child does not get better as fast as the parent thinks he or she should, the child is taken to the emergency room. At the hospital, the child gets a prescription for biaxin.

Ms. Demers admitted that she has become the peak-flow queen of Calhoun County. The mind set of some people has changed, but not much. People still believe that, since they have driven 45 miles to come to the doctor, they must get their prescription for an antibiotic or they will not be happy. On the other hand, about half the school band was on inhalers at the beginning of this semester. They were all coming to Ms. Demers and saying, “I can breathe.”

Ms. Demers has found that follow-up is the key to success in getting patients to stick with the inhalers. When “Susan” comes in to see her and she is not breathing well, Ms. Demers puts her on an inhaler. Ms. Demers then asks the child to come back the following day with the inhaler so that she can see her use it. This way, Ms. Demers can make sure that it is being used correctly. Ms. Demers told a story of one child who was holding the inhaler out in front of himself, pushing it, and walking into the mist.

Ms. Demers has also experienced parents that are afraid of inhalers. They perceive that if their child begins using one now, then he or she will need it the rest of their life.

Another problem that Ms. Demers encounters frequently in a rural community is that of logistics. She works in a brand new beautiful middle/high school which is eight miles out of town. If she calls a parent about prescribing medication for his or her child, she finds that there is no way to get the medicine to the child quickly because the mother does not have a car and the father is at work. There are no drug samples available for distribution either. Although they might get the inhalers, they always believe that they will ultimately need an antibiotic and so they do not understand why she will simply not prescribe one. In addition, a lot of these children do not qualify for Medicaid because their parents are working.

Ms. Demers has also found that you cannot take anything for granted in a rural community. She asks her patients if they have electricity, if they have water, and what kind of heat they have. Wood heat is very prevalent in her county. This is very important information to have when health-care providers start performing interventions. Ninety-nine percent of the time, parents do not want to hurt their child, but some of the triggers result from conditions which are difficult to overcome and parents do not understand what is going on. Ms. Demers considers this to be largely the fault of the health-care providers who find that it is easier to say, “Your child has bronchitis; here is some medicine.” than it is to talk about asthma.

Ms. Demers then shared with the group her frustrations concerning emergency rooms. In North Carolina, Medicaid patients would have to call their primary-care provider to get permission before taking their child to an emergency room. Usually, they would call Ms. Demers or one of the other mid-levels that ran the clinic, who would explain to them that if they took their child to the hospital because of his or her asthma, they would get a breathing treatment with a nebulizer, which is exactly the same thing that they could do at home. Ms. Demers’ office was very consistent in how it handled the parents. However, the last child from her practice that got into trouble and went to the emergency room was told that he had bronchitis, not asthma, and was given a prescription for Zithromax and a breathing treatment, and was sent home without anything else.

She then told a story about a family she knew in North Carolina. They had a teenage son with very bad asthma. Her first week in West Virginia, she walked into her exam room and found the teenager there. The family had moved to Calhoun County! She had not seen the boy all winter,

but when he came into her office he was in trouble – he was not breathing well. Ms. Demers discovered that he had not used his inhaler, rescue or otherwise, or his nebulizer in over a year. She immediately put him back on his nebulizer and called him back the next day. She found out that he could not find his medicine. She also learned that the night before, he had been taken to the emergency room in another town, where the doctor had given him an antibiotic and a prescription for Tylenol with codeine for his chest pains. Ms. Demers asked the boy if he had told the doctor that he had asthma. He said he had, but that the doctor told him that it was not asthma, it was bronchitis. Despite this, Ms. Demers put him back on his nebulizer treatments and he is doing fine now.

Ms. Demers believes that these situations occurred because there is not a consistent education process; there is not a consistent message going out to parents. This is what Ms. Demers finds the most frustrating. She looks at some of the materials coming out on asthma, and they come in the form of a 35-page book. Ms. Demers, who typically sees 35 children each day between 9:00 a.m. and 3:15 p.m., does not have time to read a 35-page book. Other health-care providers probably feel the same way.

Research suggests that the asthma rate is growing. Ms. Demers wonders if it is truly growing, or if there is simply much more awareness of the issue and primary health-care providers are finally giving that diagnosis to children, as opposed to bronchitis. Four years ago Ms. Demers was diagnosed with asthma, and now that she is treating children with asthma, she wonders if she had asthma as a child. Nobody ever gave the symptoms she experienced the “asthma” label. Even today, doctors are concerned about giving a child a label, and Ms. Demers understands this concern. In West Virginia where Ms. Demers practices, the perception is that when a health-care provider says asthma, it means the child cannot participate in sports, run, or even play. The child is supposed to sit in a chair the rest of his or her life because that is what parents were told 40 years ago and no one has helped them understand that things have changed. Ms. Demers believes that once you explain that children can be active and play and have asthma, parents will be more responsive to treating their children appropriately.

Ms. Demers feels that education is at the heart of effective asthma management. However, if health-care providers do not take the time to educate their patients and their families, very little progress on improving the incidence and management of asthma will be made. One of Ms. Demers’ recommendations is that education be made a priority in the Region III strategy. Ms. Demers feels that large organizations, such as the American Lung Association, have the ability

and experience to serve as educators in implementing the Region's strategy.

In addition, Ms. Demers feels that available educational materials and guidelines do not solicit clear or consistent information from patients and parents. When she asks a patient how many times in the last week did he cough, he cannot tell her, and neither can his mother, grandmother or anyone else. Consequently, the child may not be diagnosed correctly, because the questions asked are not phrased in a way that all people can understand them. There are three sets of questions that she believes should be asked: (1) "Is the child coughing a lot before he goes to bed at night?" (2) "When the child is out running around with the other kids, does he stop and have to catch his breath while the other kids keep going?" and (3) "When your child gets a cold in the winter, does he also get the cough, and does the cold go away, but the cough goes on and on?" Ms. Demers has had success obtaining answers to these questions, but when she asks them the questions that care providers are taught to ask, the parents and patients say "no," because it doesn't relate to them.

Ms. Demers then discussed the area in which she practices. She explained that the population is very poor and homogenous. She further explained that these people are not only poor materially, they also have a poverty of mind. They believe they are poor, they believe that there is no choice, and they believe that there are no options. This poverty of mind goes to how they perceive health care. When a mother is taught that she can give her child three nebulizer treatments before she rushes to the emergency room, she becomes empowered to control her child's health. But when a mother thinks that, because the first treatment did not work, the child must be rushed to the emergency room, the message she gets is that she is not capable of taking care of her child; that role must be entrusted to somebody else. Having trained many Mexican mothers to successfully manage their children's asthma, Ms. Demers does not see why other populations cannot be taught to do so as well. This has been particularly frustrating for Ms. Demers, who feels that unless the regional strategy can overcome this poverty of mind state, it will never get a handle on asthma, because people are always going to think that asthma is a critical situation that only a doctor can handle.

Ms. Demers believes that if you empower the parent, you empower the child. Children *can* use their peak-flow meters to understand whether they need their inhalers or not. It does not have to become a power struggle between the child and the parent. Children think that peak-flow meters are the greatest thing in the world because they take the guesswork out of asthma. Ms. Demers does not understand how people can treat asthma without peak-flow meters. Most of the children

she sees do not wheeze, they cough. Physicians would not allow diabetics to go without checking their sugar, but they seem to think asthmatics do not need to check their breathing.

Ms. Demers then described the difficulties she has experienced in obtaining peak-flow meters. She explained that to get a peak-flow meter covered by an insurance company in West Virginia, the primary health-care provider must write a letter – the request cannot be made by phone. Usually, the insurance provider does not respond, so a follow-up phone call must be made to determine why a response has not been provided. Then the provider must wait for a letter to come back from the insurance company. Once the letter is obtained, the parents must be called, a prescription written, the peak-flow meter must be ordered by the pharmacy, the parents must pick it up, and the child must be brought back to the provider's office for instruction in its use. Given this level of involvement, Ms. Demers can understand that a physician with a private practice does not have the time to follow this process to the end.

Ms. Demers suggested that insurance commissions be brought into the strategic planning process. Every state has an insurance commissioner and they have a lot of power. Insurance commissions have the authority to pass regulations and, consequently, the Region should ensure that they are adequately educated on the asthma issue. It is important to note, however, that each State has different rules. For example, in North Carolina, the primary-care provider is only required to place a phone call to the insurance company in order to obtain a peak-flow meter for a patient--a verbal approval is all that is necessary for the provider to write the prescription.

Ms. Demers feels that the Region should also place a lot of emphasis on the providers. Someone in the office, whether it be the doctor, a nurse, or an educator, must take responsibility for educating the patients and their families. Parents and children must be empowered to feel that they have control and that their asthma condition is not something that somebody else is going to take care of. Ms. Demers closed by suggesting that it really does not take that much time to educate patients and their family properly.

In response to a question, Ms. Demers pointed out that physicians treat what they are comfortable treating, and that one of the Region's focuses should be to make physicians feel comfortable in treating asthma.

6.4 *Reverend Harold Blount, MSW, Giving of Self Partnership*

Reverend Blount began by providing some background on the The Giving of Self Partnership. This community-based organization has united with three other groups – the Einstein Hospital, the LaSalle nursing program, and the Philadelphia school district – to address concerns related to asthma among minority and low-income people. The organization also has plans to complete a multipurpose community center by January, which will include a full-service health clinic with two doctors, several nurses, and everything that comes along with it.

The Reverend shared his belief that the faith community should be involved to a greater extent with issues such as asthma. His constituents are the African American youth and families that live in the neighborhoods in North Philadelphia. Based on his experience, Rev. Blount believes that a greater emphasis must be placed on research and education programs concerning asthma.

Rev. Blount then introduced his colleague, Jane Haggarty, who is his program coordinator. Ms. Haggarty began by providing more information on their organization's program – the Community Coalition for Minority Children's Health. The Coalition has worked together on a variety of issues in the past, but the central issue of asthma has helped to formalize the group's working relationship, as the various organizations have come to work together under a single source of grant funding. Ms. Haggarty explained that the grant has two components: addressing asthma morbidity and mortality, as well as the rate of infant mortality, in the area. These two goals have been linked because some of the things that can be done prenatally, such as encouraging breast feeding, conducting an environmental assessment of the home, and doing environmental interventions before the baby is born, may serve as an effective primary prevention for asthma.

The Coalition started with one particular elementary school in the Logan community, which is in the upper Northern section of Philadelphia, as the target population. It is one of the largest elementary schools in the Philadelphia area, with about 1,000 children. From Ms. Haggarty's experience working with the school, she had identified about 60 children that had asthma. However, based on the statistics and other information available, she knew that more were likely to exist.

The target population is 90 percent African American, seven percent Asian-Pacific Islander, and four percent Hispanic. Ninety percent of the students in the school are living in poverty. Most of them live in homes that were built before 1950. There was a problem with the foundations of

many of these homes sinking, although a lot of the families are still living in them. In addition, 85 percent of the families are renters, and, consequently, do not have complete control over the environment in which they are living.

The Program has three components. The first is case management. A public health nurse, a public health educator, and Ms. Haggarty work with families over the course of a year to try to increase their ability to successfully manage their asthma. The Program's goal is to help the families partner with their primary-care providers to achieve this success. This goal has been expanded to include partnering with the school, teachers, and community, as well to achieve successful asthma management.

As part of the Program, an environmental assessment is conducted. This assessment first looks at the whole house. The key is always to be realistic and affordable to these families, since they are low-income and do not have a lot of control over where they are living. In addition to identifying triggers, the Program tries to determine the extent to which each trigger impacts the life of the asthma patient. For example, before Ms. Haggarty suggests to families that they get rid of their upholstered furniture, she determines the extent to which the child really sits on it. Maybe the child spends 90 percent of his or her time in the bedroom and, therefore, the couch is really not much of an issue in terms of the child's asthma management.

The second part of the assessment focuses on the bedroom or the sleeping area. Ninety percent of the families enrolled in the Program do have a separate sleeping area with a door that closes. The Program tries to make the sleeping area a completely trigger-free zone. Ultimately, the families select what they want to do. Ms. Haggarty goes through the home with them, points out the potential triggers, and then has them pick the top five things on which they would be willing to start working. Over 50 percent of the families have someone living at home that smokes. Ms. Haggarty always tries to address this first, but it is not necessarily the most realistic target, given personal resistance. If she cannot convince the smoker to quit, she tries to get them to sign a contract stating they will agree to smoke outside of the home. The Program also offers a smoking cessation group, but participation is low and often takes months of working with people before they are open to the idea. Until people see that their children will never get complete control of their asthma as long they continue to smoke in the house, it is very difficult to get them to stop.

In addition to cigarette smoke, dust mites and cockroaches are the most common triggers seen. Ms. Haggarty tries to let the families know that every intervention they do makes a difference. In

the past, when they have received information about environmental interventions, it has usually been in a huge, overwhelming package. Families are not interested in trying to understand, and the package ends up in the trash. Ms. Haggarty emphasizes that every little bit does help and does make a difference, and encourages the family to start somewhere. People have been very open to just starting with the bedroom; it helps to confine the problem and gives them a manageable starting point.

The Program also conducts workshops for the whole community and has worked a lot with day care providers, including teaching the American Lung Association's "A is for Asthma" program. Staff are also helping day-care providers learn to manage children with asthma. Parents need to know that whoever is taking care of their children is knowledgeable about how to take care of their asthma and that the children must have their medicine with them at all times. The Program has also conducted a lot of education in the schools using the "Open Airways" program. To get around the school's concern about students missing class, Ms. Haggarty explained that the curriculum is offered as an after-school club. Despite some initial concerns, attendance has been excellent and the students have been very interested in the program.

Ms. Haggarty noted that the "Open Airways" program has also been a wonderful link to getting parents to agree to becoming part of the case-management program and letting Coalition staff come into the home. People are not generally used to the idea of home visits by the school nurse or a health educator and can be very suspicious. However, after hearing about asthma and the asthma nurse from their children every week for six weeks, the home visit makes more sense to them, and they are willing and interested in having them come in and teach them what we taught their children.

Ms. Haggarty went on to explain that the children have been so enthusiastic about the "Open Airways" program that the Coalition has developed another group called "Open Airways for Graduates." There has been tremendous attendance at the group's meetings--so much so that extra staff have been needed to help. "Open Airways for Graduates" allows for the much-needed reinforcement of everything that was taught in the general curriculum. Children cannot be expected to learn all of the information and management techniques in one or two visits; they need continuous reinforcement. Between the case-management program with families and the kids in "Open Airways" and "Open Airways for Graduates," Ms. Haggarty is confident that positive asthma management behaviors can be achieved over time.

The Program also works with teachers. Ms. Haggarty observed that many teachers had significant beliefs that were preventing them from helping students successfully manage their asthma. An asthma IQ test was given. One of the questions asked was whether a student should be sent to the school nurse every time he or she complained of symptoms, regardless of whether those symptoms could be seen. Forty-five percent of the teachers responding said no. They did not trust the students; they thought the students were simply trying to get out of class. Consequently, Ms. Haggarty noted that there is a real issue with delay of treatments in some of these schools. In response to this attitude, teachers have been told that they are not responsible for determining whether a child is having an asthma episode or not; they need to send the child to the school nurse if they are complaining.

Teachers were interested in learning. Every one of those interviewed either personally or professionally knew somebody with asthma, and they were very concerned about how to manage it in their classrooms. Teachers who were designated by the school nurse as being able to give medication were particularly interested. Principals were also interested. The Program conducted a workshop with the principals and found that they had the same common misconceptions as the teachers. The biggest misconception was the belief that asthma episodes come on suddenly, with no warning, and that children will be hunched over wheezing. These teachers and principals were taught all about early warning signs. Working with the schools and the teachers really helped children increase their ability to manage their asthma. Because they are in school such a significant portion of their day, Ms. Haggarty felt it important to address children's educators in order to increase the chance for successful asthma management.

The third component of the Program is local primary-care provider education. This was a big barrier in the past, because the primary-care providers were not following the asthma guidelines. Staff would work with families to encourage better asthma management, but when they would send the families to their primary-care provider, the families would be told that their child had bronchitis or some other non-asthma disease. The primary-care provider would tell them that the child did not need their asthma medications or perhaps only needed albuterol. When they were enrolled in the Program, most of the kids were only on albuterol; they were not on any control medications. However, most of these children were having symptoms three times a week or more and were often limited in their physical abilities. Another example occurred when children were sent out to get their flu shots. Ms. Haggarty was called by parents telling her that their primary-care provider refused to give their child the shot, because the provider would not give flu shots to children under 18. These examples demonstrate the need for better care provider

education.

Another barrier encountered was contacting the parents. Over 1,000 phone calls were made and over 5,000 flyers and letters distributed trying to identify potential children. Ms. Haggarty found that the most successful form of contact with parents was in-person contact. Program staff were present at the school for student registration and for every report card day. Registration day was the most successful, because every parent comes in on that day. Staff eventually enrolled 120 children from LaVerne elementary school.

Yet another barrier was the perception of what constitutes asthma control. Families consider their children's asthma to be under control if the child is not hunched over and wheezing, regardless of how frequently the child is using the albuterol inhaler. They also think that it is acceptable to have limited physical abilities. For example, one child stopped three times to tie his shoelaces on the way to school. This was his way of not letting his friends know that he had to take a break. When his mother finally noticed that his shoes were already tied when he was bending over to tie them, she asked him why he kept doing that. The boy said that he did it because he could not breathe – his asthma was not under control. Similarly, Ms. Haggarty has found that if parents were asked when the last time was that their child had an asthma episode, many would say it had been several years. But, when they were asked about symptoms, it turned out their children were experiencing them every day. Educating parents on what to expect in terms of controlling asthma is so important.

Schools are not aware either. If an asthmatic child is consistently missing gym classes or needs elevator passes, then it is likely that the child's asthma is not under control. It is important to get the school involved. Ms. Haggarty found that everybody has to be a part of an asthma management plan; otherwise, nobody is helping asthmatic children. Consequently, Ms. Haggarty felt that it is extremely important to clear up the confusion over what is control and what can be expected when a child's asthma is under control, particularly in terms of quality-of-life issues.

Ms. Haggarty believes that one of the Coalition's major successes has been partnering – partnering with the schools and other organizations. For example, partnering with Einstein Medical Center helped the Program reach physicians. When Ms. Haggarty first tried to contact physicians, she experienced a lot of resistance because she was a nurse. By partnering with Einstein, physicians were able to introduce Program staff to other physicians, thus allowing them to bridge some relationships. Having these people on the executive oversight committee and

having them committed as grant partners made a big difference in the Program's success, explained Ms. Haggarty.

Ms. Haggarty also shared some photographs with the group, including one of a Saturday event. She explained that, because many of their families are working, it is hard to find the time during the week to get together. So they work evenings and weekends to accommodate their families. Ms. Haggarty suggested that the Region consider expanding its working repertoire, particularly the hours staff are available to work with families, teachers, and doctors. The Saturday event shown by Ms. Haggarty was a trigger treasure hunt. Triggers and nontriggers were put on a table and the children had to trap them in a box; they really enjoyed this game. Ms. Haggarty said that they also do this in the classrooms to teach all children about asthma, which encourages more peer support and discourages teasing.

Another success was using the "Open Airways" program as an entry into the home. Almost all of the children who went through "Open Airways" are enrolled in the Program. Once the word got out, families were much more welcoming. To date, 64 children have been enrolled in the first nine months of the Program. In addition, Ms. Haggarty considers the Program to be successful in making realistic and affordable environmental interventions.

Ms. Haggarty has also found that physicians are interested in more education. Education sessions that have been conducted have been well-received, and they have helped to bridge relationships and have created opportunities for getting involved in private practices. However, physicians want more specific information on how to write an asthma action plan or how to teach the use of peak-flow meters or inhalers. Ms. Haggarty explained that she will go into a physician's office and provide this type of teaching and partnering, but she has also created a monthly newsletter that focuses on education in the office and what staff can do. Not only does this newsletter provide physicians with important information, it also keeps them aware of the Program. As a result, the Program has received many referrals from primary-care providers.

Ms. Haggarty concluded by noting that although the Community Coalition for Minority Children's Health is a small Program, she believes that it is a very good model. If it were brought to all the neighborhoods in Philadelphia, Ms. Haggarty is convinced that the city would see a lot more success.

Ms. Haggarty was asked how long she had worked with this Program and whether she has been

able to track any improvement among the children that are enrolled. She explained that the children that had been in the Program so far had not experienced any asthma-related hospitalizations or emergency room visits since their enrollment. She did caution that the Program had only existed for nine months, and explained that the data are very short-term and preliminary. She also explained that she wants the Program to begin to evaluate both the children's symptoms and their quality of life. She reiterated the Program's commitment to getting families to understand what real asthma control is. She also mentioned that they are looking at school absenteeism as another measure of the Program's success.

Another question was asked about the schools with which Ms. Haggarty is working. She explained that they didn't partner with one particular school, but rather with the whole Philadelphia school district. However, they are working with one particular school cluster. The first year of the Program included one elementary school; the Program has been expanded in its second year, and now includes a middle school and high school.

NOTE: Since there was not enough time allotted for discussion around the issue of disproportionate impact, the Conference sponsors are interested in hearing from stakeholders concerning this topic.

7. MANAGED HEALTH CARE: WAYS TO INFLUENCE CHANGE

7.1 *Mary Smith, Director, Indoor Environments Division, Office of Radiation and Indoor Air, U.S. Environmental Protection Agency*

Ms. Smith opened the session by explaining that the purpose of this panel discussion was to gain information regarding the asthma-related policies and practices of managed-care organizations. She posed two questions for the audience to consider while listening to the panelists: (1) What additional steps might health maintenance organizations be interested in taking? and (2) What would it take for other HMO's, who are not working in this area, to get interested in it?

7.2 *Alan Kohrt, M.D., Patient Management Medical Director, AETNA Health Care*

By way of background, Dr. Kohrt explained that prior to coming to AETNA, he had practiced pediatrics for 21 years in Northeast Philadelphia. A large percentage of his practice was either on Medicaid or were uninsured.

Dr. Kohrt then went on to say that managed-care organizations have the tools to help manage asthma, but that they are only tools. Health care is local and is delivered by physicians. Managed-care organizations are there to help children and adults with asthma, as well as their physicians. There are four components to managed-care:

- Utilization Management
- Disease Management
- Case Management
- Physician and Practice Improvement

In terms of utilization management, Dr. Kohrt felt that a goal should be to focus on alternative settings for care – not every child with asthma needs to be admitted to the hospital.

With regard to disease management, Dr. Kohrt explained that six to seven percent of AETNA's commercial members have asthma and 11 percent of its Medicaid members are asthmatics.

AETNA has a program in place to address asthma, which consists of:

- Identifying potential patients through a referral from a primary provider, self-referral, referral from a disease-case manager, or hospitalizations. Patients may also be identified through AETNA's early warning system, which flags anyone who has obtained inhaled steroids or other anti-inflammatory medications through its pharmacy program.

- Stratifying patients by the severity of their asthma (high, moderate, low risk).
- Educating both physicians and members. Physicians are sent letters and must give their approval for their patients to be enrolled in the disease-management program. They also earn continuing medical education (CME) credits. Both physicians and members are sent materials, including those developed by the National Asthma Program (e.g., “Early Warning Symptoms,” “The Red, Yellow, Green Warning System Developed for Patients”).
- Conducting case management. Depending on the severity of their asthma, members can receive a home health visit, as well as two visits from RNs. During these visits, the nurse educates the member, goes over their medications, and conducts an environmental assessment of the home. This begins the disease-education process and includes an important follow-up component.

The effects of the program are measured in terms of number of emergency room visits, number of asthma-related hospitalizations, and cost and quality-of-life surveys. Since it has been in effect, the program has observed a 13 percent decrease in the number of asthma-related hospital admissions.

Within its Medicaid program, AETNA has an asthma disease-specific nurse who handles all of the children and adults with asthma in New Jersey. She works directly with the families. One of the biggest obstacles that AETNA has found with this program is reaching the families – either they do not have telephones or the number they have provided is not working. They also provide an outreach nurse to work within the community to focus attention on asthma management. The nurse works with community-based organizations, schools, Head Start programs, and individual providers who have asthma patients with particularly high rates of emergency room visits or hospitalizations.

Dr. Kohrt then addressed the issue of changing physicians behavior. He explained that physicians have to value what you are telling them and value the recommendations that you are making before they will change. Secondly, he explained that changing physician behavior is extremely complex. Thirdly, Dr. Kohrt believed that it was not so much the doctors that had to change, but the system in which they work or the way in which they are working. He went on to say that if physicians do not believe that they are having a problem treating their asthmatic patients, they will not change their behavior.

Dr. Kohrt next posed the question, “Does traditional CME work to change behavior?” After

telling the audience that they would only remember 50 percent of what he had said immediately after he had stopped speaking, 20 percent eight to 12 hours after his talk, and 10 percent six weeks from now, he concluded that traditional CME does not work to change physician behavior.

In order to change behavior, the environment must be supportive. The entire office system must be changed. Dr. Kohrt recommended that physician and staff reminders be placed on the office walls; patient education reminders be used; flow sheets be put in patient charts; and labels be placed on the charts of asthmatic patients. By so doing, if an asthma patient comes in with an ear infection, the physician will be reminded to ask whether he or she received a flu shot. Dr. Kohrt has stressed that these changes must be maintained in order to be effective. The entire office staff must be targeted and understand the message and the plan, policies, and procedures for dealing with asthma patients.

AETNA is providing incentives, using the QCCS model, to encourage physician change. Physicians are given an Asthma Report Card, which evaluates what percentage of their asthma patients went to the emergency room; what percentage were admitted to the hospital; the length of the hospital stay they experienced; the percentage with prescriptions for anti-inflammatory medicines; and the percentage who had received flu shots. Increases in the capitation paid to the provider were determined by the report card. The results from these efforts to change provider behavior have been positive: the number of asthmatics receiving flu shots increased from 17 percent in 1997 to 21.6 percent in 1998. In addition, there was a decline in the number of emergency room visits and hospital admissions.

Dr. Kohrt concluded by reiterating that managed-care is just a tool to help the providers. HMOs can provide information to physicians, and staff can go into the community and work with community-based organizations, schools, and child care centers. But the real power to make a change or a difference rests with the provider, his or her staff, the family, and the community.

Dr. Kohrt responded to questions on the following topic areas:

Quality of Life Measures. Dr. Kohrt explained that AETNA uses a quality-of-life survey adopted and used for Medicare. He also explained that they are just now putting together the data to see if there have been any differences in the survey. However, he suggested that it is important to remember that a decrease in emergency room visits and hospital admissions are also indications of a positive change to a patient's quality of life.

Patient Counseling. In response to a question about physicians having enough time to counsel their patients in effective asthma management, Dr. Korht stated that provider offices should have health educators and care coordinators to help relieve the pressure on doctors. He also noted, however, that some doctors simply will not take the time to work with their patients on these types of issues.

Nurse Training. An audience member raised the issue of training nurses to conduct environmental home assessments. Dr. Kohrt explained that the nurses in the disease-management program and the Medicaid asthma program must meet specific criteria that AETNA developed. But he did admit that it was difficult to monitor and ensure continued quality once these nurses are in the community.

AETNA's Disease Management Program. Dr. Kohrt explained that patients must have physician approval before they can enroll in the program. However, few patients are unable to get the necessary approval. Once they are enrolled, they receive a peak-flow meter, a nebulizer, and a spacer (if necessary), as well as education materials.

7.3 Susan Ford, Director, Preventative Health Services, Independence Blue Cross

Ms. Ford opened her session by explaining that she had been with Independence Blue Cross (IBC) for over 10 years. Prior to assuming her current position, Ms. Ford had been the Director of Health Management Programs, which has oversight responsibilities for Independence Blue Cross' disease-management programs. Ms. Ford then stated that managed-care organizations can and do participate in projects which can contribute positively to the improvement of the health-care services offered to patients with asthma.

Ms. Ford provided the audience with some background on Independence Blue Cross. She explained that IBC is the largest health insurer in Southeastern Pennsylvania. They have 8,100 associates in 48 different locations and 11 regions. There are over four million members. Independence Blue Cross is a full-service health insurer offering HMO, PPO, Medicare, Medicaid, and indemnity insurance. The organization has a long commitment to social missions, having created the Caring Foundation for Children, which provides free or low-cost health insurance to uninsured children in the five-county Philadelphia region. Since the Caring Foundation was formed in 1990, over 70,000 children have been enrolled and 850,000 medical services have been provided. Independence Blue Cross also administers the Children's Health Insurance Program

and has formed the new Healthy Futures Program, which will help parents better understand and access their children's covered benefits and services.

The patient-management department of Independence Blue Cross conducts precertification, concurrent review, and case management functions. In addition, population-based, disease-management programs are referred to as Connections Health Management Programs. The programs are intended to connect what otherwise might be a very disconnected health-care delivery system.

Ms. Ford explained that Independence Blue Cross recently desired to enhance its Asthma Connections Programs, so the organization approached the American Lung Association (ALA). The ALA was interested in working with IBC on a joint project. Ms. Ford observed that managed-care organizations are limited in what they can do because they do not provide hands-on care. However, by entering into joint projects with groups such as ALA, these organizations can provide the tools and support to drive that care in a positive way.

Ms. Ford next discussed some of the barriers and limitations that health plans face in their ability to affect change because they are not direct care deliverers. Her organization is constantly being challenged with multiple and complex data systems, and defining or redefining how they identify their own asthma population. She explained that although managed-care organizations do possess a lot of data, they are challenged in trying to coordinate that data among their own separate data-management systems.

She explained that managed-care organizations also experience staffing and financial resource limitations. However, they found that they were able to overcome some of these barriers by successfully partnering or collaborating with other organizations. In so doing, each organization brings a unique set of assets or abilities to the table. The combination of these resources is unmatched by anything each individual organization could provide alone.

Ms. Ford then talked more specifically about the joint project between Independence Blue Cross and ALA. In this program, each of IBC's primary-care physicians receives a copy of the NAEPP Practice Guidelines for the Diagnosis and Management of Asthma. Before this project, Ms. Ford explained that IBC had assumed that these guidelines had been widely distributed; however, they discovered that this was not the case. IBC also provides each physician with a desk-top reference. This reference is intended to help physicians diagnose, classify, and manage both their

adult and pediatric asthma patients. The reference can also be used by other clinicians in the office. These tools are called desk-top references because they are intended to be left out on a desk and not stuck in some out-of-the-way place. Ms. Ford also mentioned that a template for an Asthma Action Plan was included on the back flap of the physician's desk-top reference. This was included so that physicians could copy it in their offices and customize it for their individual patients. This was an attempt by IBC to get the right tools into the physicians' hands.

Independence Blue Cross uses HEDIS 2000 criteria to identify their asthmatic population. On a side note, Ms. Ford expressed an interest in learning how other organizations have applied this new definition and any lessons they might have learned. She went on to explain that each member identified receives an educational mailing, including a customized copy of ALA's "What is Asthma?" brochure. IBC worked collaboratively with ALA to make some minor changes to this document in order to customize it for their particular membership (one modification was the inclusion of the direct telephone number to IBC's case management department). Ms. Ford noted that this collaboration was a perfect example of a situation in which an organization does not have to reinvent the wheel by creating their own materials. In addition, this is also an example of consistency in the use of tools in the health-care marketplace.

Another educational piece that went to the members was the Asthma Action Plan on the back flap of the NAEPP guidelines. IBC made individualized copies for each of their members. The message to their members was, "If you don't have one of these, take this with you to your next physician's appointment and talk to him or her about how you should respond to increasing asthma symptoms." IBC tried to hit things from multiple directions (physicians and members), in the hope that one group would read the materials and bring them to their next encounter with the other group.

In terms of their joint project with ALA, Ms. Ford explained that it was too soon to share any particular outcomes or measures. However, she did present other data, which illustrated a 25 percent improvement in how physicians classify their patients' asthma severity. She also presented information which demonstrated a 28 percent decline in the number of asthma-related hospitalizations in the last six months. These data were collected from physician questionnaires. In response to an earlier comment, Ms. Ford explained that Independence uses the American Group Practice questionnaire to get to quality-of-life issues, as well as some very specific asthma questions. These questions are directed at both physicians and members. Ms. Ford also shared data that was member self-reported, which indicated a 59 percent decline in the number of days

missed from school or work. She felt these data suggested that focused efforts, either alone or in combination with others, are resulting in progress in the care management of asthma.

Ms. Ford then shared her recommendations with the audience:

- Organized collaboration
- Nationally recognized authority
- Standardization of educational materials
- Putting aside of personal and individual agendas to maintain the primary goal of improving asthma care

Ms. Ford concluded by stressing that effective collaboration is the key to future strategic planning. She then entertained questions from the audience.

The first question concerned the rate of return on the physician's survey. Ms. Ford explained that the rate has been increasing since 1995, reaching as high as 50 percent.

Ms. Ford was then asked about member tracking. She responded that IBC has not looked at outcomes, such as hospital or emergency room visits, based on the severity of the member's asthma at the time of the enrollment in the program. She explained that the data she presented were physician-reported and thus were not population-based.

The next question concerned the case-management component of the program. Ms. Ford explained that cases were stratified as high, medium, and low; however, this was not necessarily based on the asthma severity, but rather on the workload that a case manager must put in. For example, a new referral, regardless of whether he or she is a mild, moderate, or severe asthmatic, would require the same amount of case-management work to conduct an accurate evaluation and assessment. Therefore, all new referrals are considered "high." Ms. Ford went on to explain that Independence Blue Cross has created its own case-management system and that this system does not close people out. Although the case-management component of the program lasts only a year, someone who is unstable after that time can get bounced down to a lower case-management status but stay in the system. Therefore, case managers can have several hundred cases, although they require varying amounts of activity.

Ms. Ford was asked to clarify the education component of the program. She explained that physicians and members receive a population-based mailing. The physicians get the NAEPP guidelines and the template for an Asthma Action Plan. Physicians also get a listing of their members who were identified with asthma based on the criteria IBC used, which included data on emergency room visits, hospitalizations, and pharmacy use. Members get the ALA asthma brochure, a letter, and an Asthma Action Plan.

7.4 *Michael Schaffer, Pharm.D., Director, Health Policy and Clinical Outcomes, Health Partners*

Dr. Schaffer first clarified that he was not a medical doctor, but rather a doctor of pharmacy. He then provided some background on Health Partners, which is a nonprofit managed-care organization. Health Partners covers about 120,000 patients in the Philadelphia area and was formed initially by three Philadelphia hospitals. Since then, four other partners have joined, bringing the total to seven. The age distribution in the Health Partners plan indicates that it insures a younger population than other plans. Over one-half of its population is African American and one-quarter is Hispanic.

Dr. Shaffer explained that Health Partners does not have a centralized disease-management program. Rather, each one of its owner institutions has its own program. However, Health Partners has begun the task of identifying asthmatic members and referring these members to the appropriate owner institution. Using 1998 data on medical and pharmacy claims, Health Partners identified 16,000 asthmatics, and referred the high-risk candidates to their owner institutions and to their individual physicians.

Dr. Schaffer shared with the audience a distribution of data by zip code. The prevalence of asthma in the Northern Philadelphia area was heavy, while the prevalence in the suburban areas was dramatically lower. The prevalence of asthma in the Hispanic area was also high. Dr. Schaffer then went on to discuss the work of the Albert Einstein Medical Center. He explained that the Medical Center had sent intensive case managers into the community, and that they had made a positive difference in terms of reducing hospitalizations and number of school days missed. Because of its success, Health Partners is paying additional money to the institution for each person who is kept in a disease-management program. In return, Health Partners is asking that the institution provide certain information, which can then be entered into a central database.

Dr. Schaffer concluded by offering some concrete recommendations:

- Prospectively identify at-risk individuals
- Identify risk factors beyond the scope of the claims data
- Assess environmental triggers and other socio-behavioral risk factors. Take a hard look at these factors, identify children at the highest risk, go into their homes, and do something about them.
- Evaluate interventions. Health Partners is now in the process of cementing what data elements to collect from owner institutions, which will then be placed in a central database.
- Share what works. This will ensure that the best methods of care are disseminated city wide.

Dr. Schaffer was then asked about the pharmacy benefits that Health Partners provides. He explained that the company does cover pharmaceuticals. He was then asked about bringing health-care organizations together. The panel felt that managed-care organizations were in the mood to be collaborative. However, they need a body or an institution that will bring everyone together. Both New Jersey and California were mentioned as states in which the insurance companies have come together for specific projects, such as diabetic education or immunization awareness.

A question was asked about outcomes and the currency of claims data. It was explained that 95 percent of claims data come in within 60 days of the incident. Pharmaceutical data are nearly instantaneous because of electronic processing. Several audience members were interested in barriers to intervention and education, particularly in terms of obtaining spacers, peak-flow meters, and extra inhalers for school. One questioner wanted to know why spacers were not available at pharmacies and were often not covered by insurance. The panel responded that spacers are covered by the plans that they offer, and that they were working with pharmacies to create asthma education programs. One panelist suggested that members were not always educated about their benefits; an audience member recommended that facts sheets be developed that could be given to parents and pharmacies about how to access medical benefits.

The group then discussed priorities and recommendations. The following were identified:

- Provide continuous reinforcement of treatment guidelines and use creative ways to get them into providers' hands
- Provide continuous reinforcement of patient self-compliance

- Provide incentives for providers and members to embrace guidelines and use them
- Expand asthma education to all staff in the office, including the office nurse
- Certify asthma educators
- Collaborate with other organizations like environmental protection, housing, etc.
- Educate staff of managed-care organizations and provide them with tools to change the environment. Develop a list of regional contacts.
- Identify environmental risk factors, particularly those not currently being evaluated
- Develop disease-specific quality-of-life measures
- Provide better training opportunities for case managers, such as “Trigger Hunt Simulation” or “How to Investigate for Triggers”
- Review diagnoses to ensure that asthmatic children are not missed because they are inaccurately diagnosed
- Ensure that devices are available at clinician offices to dispense to patients, and that such devices are covered by insurance
- Investigate how the school environment impacts the child
- Develop policies that will allow children to carry their asthma medications in schools
- Educate children in schools about asthma
- Promote the use of asthma action plans and make sure school nurses are aware of them
- Share health information with school nurses
- Ensure that information is language and reading-level appropriate
- Conduct cost-benefit analyses of disease-management programs
- Create minimum education standards for all asthmatics
- Streamline the process of dealing with managed-care organizations

In addition to identifying these priorities, the audience also discussed several other issues. There was a great deal of concern about insurance companies not covering a second spacer or inhaler for school use. The panel explained that two inhalers, spacers, and even peak-flow meters are often covered. There was also a lot of discussion about providing health information to school nurses, although one audience member noted that many school districts are eliminating these positions to save money. The audience was also interested in why some children were not covered by disease-management programs. The panel explained that these programs were not necessarily part of the standard insurance package purchased by a self-insured employer.

The panel was also asked what they would suggest to other managed-care organizations to encourage them to adopt aggressive asthma-management programs. One panelist said that the barriers related to staff and cost can be overcome by collaborating with others. Another panelist noted that, although some barriers are financial, others have to do with just getting into homes to help asthmatic children. He suggested working through community-based organizations to set up meetings among parents, children, and case managers within the provider's office during a regular office visit. All panelists agreed that disease-management programs have shown positive patient outcomes and considered that fact to be extremely persuasive.

8. SETTING PRIORITIES

Dr. Kessel began this final session by noting that the network and collaboration aspects of the Conference had been a great success. 148¹ persons were present at the Conference, representing every state in Region III and a vast array of domains and disciplines, including nursing, physicians, advocacy groups, HMOs, payers, managers, governments, state and local health departments, etc. He advised the group to leave with a sense of responsibility – to consider the Conference a stop along the way, a beginning and not an end. Dr. Kessel observed that the Conference had caused a lot of people to work together and to work in unusual relationships. He then charged the group to think about what they will do when they get back to their offices. He encouraged them to maintain the energy, good will, and intellectual capital that had been generated over the past two days. He also expressed his intention to reconvene a smaller group at the end of January to check on the progress made to implement the recommendations and priorities identified by the group.

Dr. Kessel then explained that a list of commitments had been generated, which covered much of what had resulted from the Conference. These commitments were organized into five domains, each of which highlighted the issues and concerns of the group. Dr. Kessel observed that the list shows the diversity of the topics that were discussed and the recommendations that were made. Each domain and the commitments associated with it are identified below.

8.1 Data and Monitoring (DM)

- Key Information in Decision Making
- Public/Private Data Sharing
- Data Quality
- Meaningful Measures
- Resources and Infrastructure
- Local Air Quality Information Applications
- Technology

8.2 Education and Communications (EC)

- Standardized Educational Materials
- Provider Education
 - Child Care Professionals

¹While Dr. Kessel indicated that 148 participants attended the conference, the actual number of attendees was 168.

- School Professionals
- Health-care Professionals
- Health-care Managers and Payers
- Community Education
 - Parents
 - Family Centers
 - Faith Communities
- Patient Education
- Media Education
- Asthma Education Certification

8.3 Health Care (HC)

- Primary Care
 - Guidelines
 - CME
 - Environmental Prescriptions
- Community
 - Home Visiting
- School Health Services
- Pharmacists and Pharmaceutical Manufacturers
- Medication Policies and Practices

8.4 Environment (E)

- Housing Conditions and Housing Code Enforcement
- School Buildings
- Environmental Tobacco Smoke
- Legislation
- Occupational Exposures
- Air Quality - Indoor and Ambient
- Local Environmental Interventions

8.5 Research (R)

- Accurate Diagnosis
- Accurate Treatment
- Follow-up and Follow through
- Innovative Education Models
- Barriers to Care
- Optimizing Care Guidelines
- Cultural Diversity
- Outcome Measures
- Alternative Treatments
- Regional, Rural, Urban Environments
- Architectural Designs
- Education and Training Materials

Ms. Wright then invited the audience to indicate their interest in making a commitment to continuing work in one or more of these topic areas. She asked the audience to express their interest by signing their name or placing their business card next to those issues or concerns in which they were willing to continue work on the development of a Regional strategy. The results of this exercise are presented in Appendix B.

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THE COMMITMENTS - Appendix B

DATA & MONITORING (4)

1. Key Information for Decision Making
(2)
2. Public/Private Data Sharing
3. Data Quality (1)
4. Meaningful Measures (1)
5. Resources and Infrastructure
6. Local Air Quality Information Appl.
7. Technology

EDUCATION & COMMUNICATION (18)

- All (2)
- 1.01 Standardized Educat. Materials (6)
 - 1.02 Provider Education
 1. Childcare Professionals (1)
 2. School Professionals (3)
 3. Health Care Professionals
 4. Health Care Managers & Payers (7)
 3. Community Education (2)
 - a. Parents (2)
 - b. Family Centers (3)
 - c. Faith Communities (5)
 4. Patient Education (7)
 5. Media Education (4)
 6. Asthma Education Certification (6)

HEALTH CARE (21)

- All (3)
1. Primary Care (1)
 - a. Guidelines
 - b. CME
 - c. Env. Prescriptions (1)
 2. Community (2)
 - a. Home Visiting (3)
 3. School Health Services (8)
 4. Pharmacists & Pharmaceutical Manufacturers (2)
 5. Medication Policies and Practices (1)
- Partnerships with payers (7)
 - Insurance commissioners (2)
 - State and local health departments (2)

ENVIRONMENT (14)

1. Housing Conditions and Housing Code Enforcement
2. School Buildings (7)
3. Environmental Tobacco Smoke (5)
4. Legislation
5. Occupational Exposures
6. Air Quality – Indoor and Ambient (4)
7. Local Environmental Interventions (1)

RESEARCH (7)

1. Accurate Diagnosis
2. Accurate Treatment
3. Follow-up and Follow through
4. Innovation Education Models (3)
5. Barriers to Care (2)
6. Optimizing Care Guidelines (2)
7. Cultural Diversity (3)
8. Outcome Measures (2)
9. Alternative Treatments
10. Regional, Rural, Urban Env. (1)
11. Architectural Designs
12. Education and Training Methods (2)

Other

1. Coordination/Collaboration of managed care organizations (2)
2. Insurance commissioners to promulgate rules
 - HUD/DHHS/EPA collaboration
 - DHHS to convene state health departments

Steering Committee (14)

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